

AN EVALUATION OF RECOVERY AFTER HYSTERECTOMY

BY

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Abstract

Background

A hysterectomy for benign disease can be vaginal, abdominal or laparoscopic depending on the incision used. The recovery from each type is traditionally believed to be different by health care professionals based principally on the incision used. We know that the beliefs of health care professionals are an important determinant of recovery from surgery (2). It may be that differences in recovery from types of hysterectomy are due to different advice from health care professionals prior to surgery, rather than the different incisions alone.

Aims:

What are the beliefs and experiences of women who have a hysterectomy and the practices and beliefs of health care professionals?

What is the evidence for psychological preparation for surgery?

Methods

1. To examine factors which might affect return to work after a hysterectomy.

A quantitative retrospective structured questionnaire

2. To examine the beliefs and practices of health care professionals with respect to hysterectomy through the abdominal, vaginal and laparoscopic routes.

A quantitative retrospective structured questionnaire

3. To explore the expectations, beliefs and experiences of women who have a hysterectomy through the abdominal, vaginal and laparoscopic routes.

Qualitative semi-structured interviews and validated quality of life questionnaires, anxiety and specific disease related questionnaires at various time points before and after hysterectomy.

4. To compare the literature on psychological interventions for surgical recovery

Systematic review of literature.

Results

There was no significant difference in return to work experience for women based on type of employment and incapacity pay. There is a great deal of variation between the advice given for recovery by UK gynaecologists and nurses at Birmingham Women's hospital, particularly after 1 week post-surgery. Regardless of the route of surgery, the expectations and fears of women are similar and that they rely on health care professionals to guide them with advice. Their experience confirmed conflicting advice from health care professionals and varied recovery experiences based on the individual rather than route of surgery. Women who had a vaginal hysterectomy had specific concerns around sitting, the group who had a laparoscopic route had a lower length of stay and women who had an abdominal hysterectomy had higher anxiety scores ($P = 0.003$). Mean quality of life scores by EQ5 were not different based on route of surgery (pre-surgery $P = 0.4446$, 1 week $P = 0.447$, 4 weeks $P = 0.876$, 12 weeks $P = 0.850$). Fewer women felt steady at 3 months after an abdominal hysterectomy than after a vaginal or laparoscopic hysterectomy. The systematic review to compare psychological interventions for recovery after gynaecological shows a reduced length of stay [$P = 0.03$,

5.65 (-10.82 to -0.48)] and reduced trait anxiety intervention [$P < 0.00001$, mean difference 7.78 (7.19, 10.61)] for women who have psychological interventions. The interventions themselves were varied.

Dedication

This thesis is dedicated to my son Arran who grew up with my work, spent research days at home with me instead of the usual play dates and remains my motivation. To John who endured many years of work and to Duncan who has supported me to complete this work.

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I would like to acknowledge the contribution of my second supervisor at the time, Rachel Powell for her contribution to the outline and plan of literature search for the systematic review in chapter 7. It was part of a larger registered and published Cochrane review protocol.

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Contents

	Page
List of tables	2
List of figures	5
List of appendices	10
Chapter 1 Overview	11
Chapter 1b Methodologies	24
Chapter 2 Return to work: a qualitative analysis.	33
Chapter 3 Health care professionals' beliefs and practices about recovery after hysterectomy: A quantitative cross sectional study	52
.	
Chapter 4 Experiences of women who have a hysterectomy: a qualitative interview study	97
Chapter 5 Validated health status questionnaires to women who have had a hysterectomy	176
Chapter 6 Anxiety and surgery: a validated survey to women who have had a hysterectomy	242
Chapter 7 A systematic review of psychological preparation for recovery after gynaecological surgery	258
Chapter 8 Discussion and conclusions	296
References	306
Appendices	316

List of tables	Page number
----------------	-------------

Chapter 2

Table 2.1	Return to work after hysterectomy for heavy menstrual bleeding	49
Table 2.2	Mean time back to work according to type of organisation	50
Table 2.3	Type of sick pay according to employment in public or private organisation	50
Table 2.4	Mean time back to work according to type of sick pay	51
Table 2.5	Mean time of return to work after hysterectomy with consultants	51

Chapter 3

Table 3.1	Number of inpatient days gynaecologists would routinely advise after different types of hysterectomy	63
Table 3.2	Advice about number of weeks patients will need care at home after different types of hysterectomy	65
Table 3.3	Advice after abdominal hysterectomy for physical recovery	66
Table 3.4	Advice after vaginal hysterectomy for physical recovery	69
Table 3.5	Advice after laparoscopic hysterectomy for physical recovery	71

Table 3.6	How would you routinely counsel your patients regarding numbers of post-operative days stay in hospital?	82
Table 3.7	How many weeks of care at home would you advise	84
Table 3.8	Number of weeks for advice after abdominal hysterectomy for physical recovery	86
Table 3.9	Number of weeks for advice after vaginal hysterectomy physical recovery	88
Table 3.10	Number of weeks for advice after laparoscopic hysterectomy physical recovery	90
Chapter 4		
Table 4.1	Codes of analysis	106
Chapter 5		
Table 5.1	Participants	181
Table 5.2	Number of women who reported problems in EQ5 at each time point	181
Table 5.3	Mean EQ5 scores at each time point	182
Table 5.4	ANOVA for mean EQ5 VAS scores according to route of hysterectomy and time point	183
Table 5.5	Total outcome scale scores	235
Table 5.6	Quality of life/satisfaction scale scores	236
Table 5.7	ANOVA of mean change in global evaluation Of symptoms before and after surgery	237
Table 5.8	ANOVA for mean scores by route of surgery	237

Chapter 6

Table 6.1	Demographics	248
Table 6.2	Mean STAI scores at time points	249
Table 6.3	Significant ANOVA by question and route of hysterectomy for STAIT anxiety	250
Table 6.4	Significant ANOVA by question and route of Hysterectomy for trait anxiety, 1 week post operation	252
Table 6.5	Significant ANOVA by question and route of Hysterectomy STAIT and TRAIT anxiety 3 months post operation	253

Chapter 7

Table 7.1	Characteristics of included studies	256
-----------	-------------------------------------	-----

List of figures	Page number
Chapter 1	
Figure 1.1	Schematic difference between qualitative And quantitative research methodology 29
Chapter 2	
Figure 2.1	Box plot of mean return to work time by operating consultant 42
Figure 2.2	Perception of return to work, actual mean time Of return to work and operating consultant 44
Figure 2.3	Patient perception of return to work and actual mean time of return 46
Chapter 3	
Figure 3.1	Regional distribution of responses 73
Figure 3.2	Proportion of gynaecologists who perform types of hysterectomy 74
Figure 3.3	Regional variation in decision for route of hysterectomy 75
Figure 3.4	Experience level and decision for route of hysterectomy 76
Figure 3.5	Regional variations in offering a routine follow up appointment 77
Figure 3.6	Variations in follow up appointment and grade 78
Figure 3.7	Regional variations in reasons to offer routine follow up appointment 79
Figure 3.8	Variations in decision making for offering A follow up appointment and experience in grade 80

Chapter 5

Figure 5.1	SF12 1 pre-surgery	186
Figure 5.2	SF12 2 pre-surgery	187
Figure 5.3	SF12 3 pre-surgery	188
Figure 5.4	SF12 4 pre-surgery	189
Figure 5.5	SF12 5 pre-surgery	190
Figure 5.6	SF12 6 pre-surgery	191
Figure 5.7	SF12 7 pre-surgery	192
Figure 5.8	SF12 8 pre-surgery	193
Figure 5.9	SF12 9 pre-surgery	194
Figure 5.10	SF12 10 pre-surgery	195
Figure 5.11	SF12 11 pre-surgery	196
Figure 5.12	SF12 12 pre-surgery	197
Figure 5.13	SF12 1 at 1 week	198
Figure 5.14	SF12 2 at 1 week	199
Figure 5.15	SF12 3 at 1 week	200
Figure 5.16	SF12 4 at 1 week	201
Figure 5.17	SF12 5 at 1 week	202
Figure 5.18	SF12 6 at 1 week	203
Figure 5.19	SF12 7 at 1 week	204
Figure 5.20	SF12 8 at 1 week	205
Figure 5.21	SF12 9 at 1 week	206
Figure 5.22	SF12 10 at 1 week	207
Figure 5.23	SF12 11 at 1 week	208

Chapter 5

Figure 5.24	SF12 12 at 1 week	209
Figure 5.25	SF12 1 at 2 months	210
Figure 5.26	SF12 2 at 2 months	211
Figure 5.27	SF12 3 at 2 months	212
Figure 5.28	SF12 4 at 2 months	213
Figure 5.29	SF12 5 at 2 months	214
Figure 5.30	SF12 6 at 2 months	215
Figure 5.31	SF12 7 at 2 months	216
Figure 5.32	SF12 8 at 2 months	217
Figure 5.33	SF12 9 at 2 months	218
Figure 5.34	SF12 10 at 2 months	219
Figure 5.35	SF12 11 at 2 months	220
Figure 5.36	SF12 12 at 2 months	221
Figure 5.37	SF12 1 at 3 months	222
Figure 5.38	SF12 2 at 3 months	223
Figure 5.39	SF12 3 at 3 months	224
Figure 5.40	SF12 4 at 3 months	225
Figure 5.41	SF12 5 at 3 months	226
Figure 5.42	SF12 6 at 3 months	227
Figure 5.43	SF12 7 at 3 months	228
Figure 5.44	SF12 8 at 3 months	229
Figure 5.45	SF12 9 at 3 months	230
Figure 5.46	SF12 10 at 3 months	231
Figure 5.47	SF12 11 at 3 months	232

Figure 4.48	SF12 10 at 3 months	233
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Chapter 7

Figure 7.1	Process from initial search to final inclusion for psychological preparation in gynaecology surgery	270
Figure 7.2	Pain at 24 hours measured by visual analogue scale	277
Figure 7.3	Pain measured by morphine use in mg	278
Figure 7.4	Behavioural recovery: time to walking	279
Figure 7.5	Behavioural recovery: wellbeing day 1 post surgery	280
Figure 7.6	Behavioural recovery: fatigue day 1	281
Figure 7.7	Negative affect: STAI Trait questionnaire	282
Figure 7.8	Negative affect: nausea and vomiting day 1	283
Figure 7.9	Length of stay	284
Figure 7.10	Risk of bias	285
Figure 7.11	Funnel plot pain VAS	286
Figure 7.12	Funnel plot morphine use (mg)	287
Figure 7.13	Funnel plot time to walking	288
Figure 7.14	Funnel plot wellbeing day 1	289
Figure 7.15	Funnel plot Nausea and vomiting	290
Figure 7.16	Funnel plot fatigue day 1	291
Figure 7.17	Funnel plot STAI trait	292
Figure 7.18	Funnel plot length of stay	293

List of Appendices	Page numbers
Appendix 1 Sponsor authorisation	317
Appendix 2 Participants information sheet	318
Return to work questionnaire	
Appendix 3 Return to work questionnaire	320
Appendix 4 Health care professional participant information sheet	324
Appendix 5 Invitation letter to health care professionals	326
Appendix 6 Questionnaire to UK Gynaecologists	327
Appendix 7 Questionnaires to General Practitioners	329
Appendix 8 Questionnaire to nursing staff	331
Appendix 9 Participant information sheet interviews	332
Appendix 10 Consent form Expectations & Experience	335
Of Women who have had hysterectomy	
Appendix 11 Consent Form Recovery from hysterectomy	336
Appendix 12 Interview schedule pre-operation	337
Appendix 13 Interview schedule post operation	338
Appendix 14 SF12 Short form	340
Appendix 15 EQ 5 Questionnaire	343
Appendix 16 STAI questionnaire	344
Appendix 17 Menorrhagia Outcomes Questionnaire	348
Appendix 18 Systematic review data extraction form	352
Appendix 19 Ethics application	355
Appendix 20 Cochrane Protocol	398

Chapter 1: Overview

Recovery from surgery

Surgery induces physiological and psychological stresses to the body which are known to affect organ function and recovery. Perioperative pathophysiology is multifactorial contributing to postoperative morbidity, length of stay in hospital, and convalescence (1). This thesis is the study of experiences of recovery from different routes of hysterectomy, the beliefs of health care professionals around recovery from hysterectomy and the actual experiences of patients who undergo a hysterectomy.

Hysterectomy

Hysterectomy is one of the most common gynaecological procedures performed in the non-pregnant woman. It involves the removal of the womb (uterus) combined sometimes with removal of the ovaries as well. It can be performed through an incision in the abdomen, vagina or by key hole surgery using a laparoscopic assisted method. The incision is often decided upon by the indication for the hysterectomy, the surgical expertise of the surgeon and their beliefs. Recovery from the various routes of hysterectomy is believed to be different anecdotally by health care professionals and

patients, in order to understand why this may be the case, some understanding of the anatomy of hysterectomy is useful.

Anatomy of a hysterectomy

The uterus is supported by the uterosacral ligaments and the transverse cervical ligaments at the level of the cervix. It is attached to the pelvic side walls by the round ligament and ovarian pedicle, which houses some of its blood supply from the ovarian vessels. The remainder of its blood supply is from the internal iliac vessels which enter via the broad ligament either side in the form of the uterine vessels. Any type of hysterectomy involves 1. ligating the blood supply at the ovarian and uterine vessels, 2. exposing the uterus by reflecting the bladder in the utero-vesical peritoneal fold with concurrent reflection of the ureters and 3. Releasing the supports of the uterus at the round, utero-sacral and transverse cervical ligaments. Regardless of the abdominal incision, the actual procedure for the hysterectomy is the same for all types.

Hysterectomy can be carried out via the abdominal, laparoscopic or vaginal routes. In a total abdominal hysterectomy, the abdominal wall is opened which is believed to add to the length of recovery and mobility of the patient afterwards. This is due to the fact that the abdominal wall forms part of the core strength of the body which is under strain during any movement post-surgery. In a laparoscopic procedure, the abdominal incisions are small and do not disrupt the abdominal wall strength and function as much, leading to the assumption that recovery is faster. In a vaginal hysterectomy, there are no abdominal incisions, instead all incisions are in the vagina, and therefore is not under the same strain as the abdominal wall incisions, possibly leading to faster recovery.

Recovery advice from hysterectomy

Traditional recovery relies on advice given by health care professionals in the form of verbal and leaflets. Many units have a pre-operative service where patients are seen by pre-operative nurses who spend time going through what to expect during recovery and how to aid recovery. At BWH, the pre-operative service is run by specialist nurses who explain the procedure around hysterectomy including practicalities of what to bring into hospital, how long to expect to stay, what to expect on the ward and what to expect during recovery. This is supplemented by patient information leaflets which outline how to aid recovery for example by early mobilisation, rehydration and pain relief. The advice relies on the experience of the nurse giving it, although it is structured around a guidance framework in a protocol. There are no agreed definitions of recovery time nor return to normality.

Enhancing recovery from surgery in general

Enhancing recovery is a desirable outcome for patients and the health system leading to a number of studies to how to improve recovery. There is already evidence that a formal enhanced recovery (ER) programme (or ‘fast track’) for surgery improves recovery and reduces hospital stay. ER is now a recognised model of care advocated by the NHS Institute for Innovation and Improvement (2) for the elective surgery pathway which aims to reduce the physiological and psychological stress responses during surgery to minimise organ dysfunction and aid faster recovery. The pathway was first described by Kehlet in 1990 (3) in a Danish model for colorectal patients taking into account the decision for surgery, surgical work up, anaesthetic, surgery post-operative care and advice for the recovery period. In the UK, the ESTReP (Enhanced Surgical Treatment

and Recovery Programme) has transformed the way in which colorectal surgery is delivered (4). The programme combines known clinical predictors of recovery (such as early feeding after surgery, not using nasogastric tubes or surgical drains) with positive psychological factors such as patient education and health promotion. The ESTReP programme has led to a reduction in the average hospital stay from 9-10 days per patient to 6 days. The authors of the study conclude that this has helped to generate extra bed space to treat more patients, and under the payment by results scheme, has generated more income for their trusts as well as to help meet 18-week targets. They have shown that the programme is cost efficient based on the daily cost on a general or surgical ward of £400, and have gained support from the Department of Health.

Further programmes have now been developed with a variety of components of the ER pathway. They have been compared in two meta-analyses, Varadhan et al's review included 6 randomised controlled trials (RCTs) with a total of 452 patients (5). This review found a significant reduction in length of hospital stay (weighted mean difference [MD] -2.55, 95% CI -3.24 to -1.85) and complication rates (RR 0.53, 95% CI 0.44-0.64) in the ER group if at least 4 individual elements of the pathway were implemented. The second meta-analysis by Gouvas et al looked at 11 studies including 4 RCTs and 7 controlled clinical trials with a total of 1021 patients (6). It also found a significant reduction in hospital stay (weighted MD -2.47, CI -3.43—-1.48) without an increase in re-admission rates or mortality.

A Cochrane review of ER in gynaecological cancer (7) concluded that there were no RCTs of ER in this context and The Enhanced Recovery Partnership Programme was set up as a partnership with the Department of Health, the National Cancer Action Team, NHS Improvement and the NHS Institute of Innovation and Improvement in 2009-2011. This initiative included studies in gynaecology, urology and musculo-skeletal surgery. The ER pathway considers the pre-operative period which includes a risk assessment and opportunity to provide information and psychological preparation. The discharge plan is criteria based upon mobilisation, control of pain by oral analgesia, passing flatus and being able to eat and drink. In 2012, the the Enhanced Recovery After Surgery (ERAS) Society, International Association for Surgical Metabolism and Nutrition (IASMEN) and European Society for Clinical Nutrition and Metabolism (ESPEN) published guidelines for peri-operative care in colonic surgery (8) It is recommended that patients should be given Preadmission information, education and counselling regarding practical advice to aid recovery, diminish fear and anxiety and expected length of time until they return to normal function. When a Cochrane review did not recommend the ERAS programme as the new standard of care due to the lack of published trials, a meta-analysis of 16 trials and 2376 patients was published confirming a reduction in length of stay and morbidity rates without an increase in readmission rates.

Recovery from gynaecological surgery

In 2016, Lena Wijk(11) published how enhanced recovery from gynaecology oncology could be applied to benign gynaecology . Further studies looked at enhanced recovery

after ovarian cancer surgery with early feeding improving bowel function and nutritional status (12).

Despite these recommendations in other surgical specialities and an opinion paper from the Royal College of Obstetricians and Gynaecologists UK (RCOG) there is no agreed national evidence based guideline for enhanced recovery in benign gynaecology surgery, and in particular around long term recovery to normal function (9) (10). NICE have published guidance in a 24 hour discharge programme after Caesarean Section. There are a number of published local enhanced recovery programmes after Caesarean (13) and the Scottish Government guidelines (14) which publish an increase in 24 hour discharge using their programme from 5% to 33% .

Steps for Enhanced recovery (ER)

Traditionally ER has a number of components:

1. Pre-operative education
2. Carbohydrate drinks
3. Fluid balance and warming
4. Early feeding
5. Removing tubes early
6. Early mobilisation

This thesis considers the first step of pre-operative education, including whether better information and counselling with psychological preparation could alter behaviour to improve recovery from hysterectomy in the long term beyond the traditional boundaries of ER which is discharge from hospital. Enhanced recovery programmes have been

established and shown to reduce length of stay and morbidity for benign gynaecology procedures (15). A Cochrane review of approaches to hysterectomy (16) found a shorter hospital stay in women who have had a vaginal rather than a laparoscopic assisted or abdominal hysterectomy and the National Institute for Clinical Excellence (NICE) has recommended a vaginal approach as first line (17). Regardless of this, in the real life pragmatic situation, hospital statistics report that women who have undergone a vaginal hysterectomy, with no abdominal incisions, have an average post-operative stay of 3.2 days in England, which is longer than the laparoscopic approach and not much different to the stay after the abdominal route (HES Statistics 2012 (18)) and NHS Choices advise between 1 and 4 days for a laparoscopic or vaginal hysterectomy and 5 days for an abdominal hysterectomy (19).

This may indicate that in strictly controlled experimental designs clinicians are potentially achieving optimum care efficiency through their beliefs about therapy and through the inadvertent physiological and psychological preparation of all patients. This could be in the form of stringent trial inclusion and consent procedures with increased access to support mechanisms and follow up. It may be that patients' and health care professionals' beliefs and expectations of recovery play a more significant part in what actually occurs outside clinical trial settings. Aspects of this could be amenable to psychological intervention to improve recovery outcomes.

ER programmes consider psychological interventions by involving the patient at every step of their surgery from planning to recovery to provide women with all the information

and support they require regarding treatment options, the surgery, recovery and discharge.

Psychological preparation

Psychological preparation incorporates a range of strategies designed to influence how a person feels, thinks or acts (emotions, cognitions or behaviours). The benefits of psychological preparation for surgery have been evaluated in a meta-analysis. It identified many different types of psychological preparation, including procedural information, sensation information, behavioural instruction, hypnotic and relaxation training, psychotherapeutic interventions and cognitive behavioural approaches. They were found to be beneficial for a range of outcome variables such as negative affect, pain, and pain medication, length of hospital stay, behavioural recovery, clinical recovery, physiological indices and satisfaction. Psychological interventions consider people's cognition, beliefs of control, empowerment and self-efficacy and the behaviours they associate with them.

Control

The locus of control is a psychological term referring to the extent to which individuals believe they control events that affect them. People can have a perceived internal or external locus of control. People with external locus of control will believe strongly in other people, fate and in their destiny, whereas someone with a strong internal locus of control will believe that they have the ability to influence their own future. Information seeking is more common in people who have an internal locus of control. They benefit

from knowing more information and are able to reduce their anxiety levels about forthcoming surgery, whereas the same information may increase the anxiety levels of someone with an external locus of control as they may rather not know the details (20). A shorter time interval to achieving a straight leg raise was found with patients who had an internal locus of control after total knee surgery (21). The effect of psychological preparation before surgery is questionable on patients with an external health locus of control (22). A consideration of the individual's locus of control can be made through offering a choice of information to reduce anxiety and to increase their ability to cope (23).

Coping strategies

The patient's coping tendency has also been studied in relation to the information patients need. People can cope with situations through mainly problem focused strategies or emotional focused strategies. Those who use problem focused strategies make plans to improve the situation and feel better when these are followed through. Emotional focused individuals tend to alter their own cognitive interpretation of the situation rather than change it, for example, 'looking at the bright side' (24). It may be that there is a continuum of control and coping strategies, which may also be influenced by the situation of undergoing surgery and by the feeling of conforming to social bias (assuming the sick role of being a patient). Research is needed into whether psychological support is more effective if matched with coping styles.

Empowerment and self-efficacy

In the past, patient education followed the traditional disease based model, where the provider was the expert who decided what information and how much of it the patient should receive. The provider becomes the primary decision maker and problem solver. Outcomes of this model are the patient's compliance with the provider's suggestion. In an empowerment model, health providers assist patients in gaining knowledge, developing skills and identifying resources. Empowerment enables others to take control of their own lives. This model recognises the psychosocial as well as the physical aspects of health and disease. Empowerment and self-efficacy are closely related constructs. Self-efficacy is the belief that you can effectively perform a given behaviour to produce the desired outcome (24). Motivation and perseverance is dependent on the individual's evaluation of their self-efficacy. If the individual does not believe they can perform behaviour, their motivation will decrease.

Using psychological interventions to improve the quality of post-operative recovery.

Although psychological interventions have been shown to improve outcomes, it would be important to establish which interventions improve which outcome. There is much heterogeneity among studies in their definition of a favourable recovery outcome, and what a favourable outcome might be to clinicians and patients. Recovery has many components including measurable clinical aspects such as vital observations, normalising of test parameters, the use of analgesia, return of physiological function such as passing

urine or opening their bowels, number of days as an inpatient and mobility. Clinical interventions need to be evaluated for quality as well as importance and value to patients. From the perspective of the patient, a favourable outcome may be more related to important aspects of their lives such as being able to sleep normally, looking after their families, socialising, feeling emotionally back to normal or being able to go back to work. In the past, patient education followed the traditional disease based model, where the provider was the expert who decided what information and how much of it the patient should receive. The provider becomes the primary decision maker and problem solver. Outcomes of this model are the patient's compliance with the provider's suggestion. In an empowerment model, health providers assist patients in gaining knowledge, developing skills and identifying resources. Empowerment enables patients to take control of their own lives. This model recognises the psychosocial as well as the physical aspects of health and disease. Empowerment and self-efficacy (the belief in one's ability to succeed or accomplish a task) are closely related constructs which can affect behaviour. Psychological interventions which increase empowerment and self-efficacy could be a cost effective way of improving those aspects of recovery which the patients value as well as traditional clinical measures. More research is needed into which psychological interventions improve which recovery outcomes. Through qualitative in-depth analysis of patient's views and experiences, we can understand their recovery and which outcomes are valued by them, and how they perceive their experiences to influence recovery.

Psychological preparation has been shown to be an important factor in the patient's surgical experience. These can be affected by the beliefs of health care providers in the

way they counsel and advise their patients (25). With an increasing drive towards a shorter length of stay in all specialities, efficient patient preparation is an important area. In the example of the route taken for hysterectomy, operative incision itself does not seem to account for the differences in recovery and the discrepancy between the everyday clinical situation and that of clinical trials. Psychological variables in the patient which are influenced by the beliefs and practices of health care professionals could play a part in accounting for these differences. The rigorous consent procedures in clinical trials and the participant support facilities through access to health care professionals and researchers as well as activities such as newsletters will have psychological consequences on the patients involved, regardless of which treatment arm they are in. This could account for the better outcomes seen in trials. Recovery outcomes could be improved in real life situations through the use of psychological interventions aimed at recovery outcomes which are valued by patients in particular, the use of well-designed information giving, cognitive therapy and emotion focussed therapy to match those seen in clinical trials.

Research Aims:

1. To examine factors which might affect return to work after a hysterectomy from heavy menstrual bleeding.
2. To examine the beliefs and practices of health care professionals with respect to hysterectomy through the abdominal, vaginal and laparoscopic routes.
3. To explore the expectations, beliefs and experiences of women who have a hysterectomy through the abdominal, vaginal and laparoscopic routes.

4. To search the literature in a systematic way for psychological interventions which may influence recovery after hysterectomy.

This thesis presents in each chapter, the background to each research aim, the study and findings with a discussion and conclusion of each. It will then consider how each of these studies has contributed to the overall understanding of recovery from hysterectomy for heavy menstrual bleeding using the different surgical routes and the implications for patients, future research and clinical practice.

Chapter 1b

Methodologies

Methodologies chosen for this study by research aims:

5. To examine factors which might affect return to work after a hysterectomy.

A quantitative retrospective structured questionnaire was chosen to answer these questions which included closed questioning for demographic data and outcome measures.

6. To examine the beliefs and practices of health care professionals with respect to hysterectomy through the abdominal, vaginal and laparoscopic routes.

A quantitative retrospective structured questionnaire was chosen to answer these questions which included closed questioning for demographic data and outcome measures.

7. To explore the expectations, beliefs and experiences of women who have a hysterectomy through the abdominal, vaginal and laparoscopic routes.

This part of the study included qualitative semi-structured interviews which covered the expectations, beliefs and experiences of women as well as considering physical emotional, social and sexual aspects of recovery. The interviews were carried out before and after the hysterectomy with each woman.

It also used validated quality of life questionnaires, anxiety and specific disease related questionnaires at various time points before and after hysterectomy, analysed in a quantitative method.

8. To compare the literature on psychological interventions for surgical recovery

Using systematic review of literature.

Background on qualitative research methodology

As a health care professional, I am trained and familiar with the methodology of quantitative research and systematic review, however, I have limited experience of the basis and methodology of qualitative research, and hence I feel I need to explore this topic in this part of the introduction.

Qualitative research aims to answer questions of ‘why and how’ through in depth exploration and understanding of human behaviour. Shank (26) defines qualitative research as “a form of systematic empirical inquiry into meaning”. By *systematic* he means “planned, ordered and public”; following established methodologies. Denzin and Lincoln (27) suggest that qualitative research involves an *interpretive and naturalistic* approach: “This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them”. In order to study in the naturalist setting, the researcher needs to enter that setting. In this way, qualitative research is different from quantitative research, where the researcher attempts to study a phenomenon from a position outside the research setting so that the researcher does not bring any effect such as bias to the setting (figure 1).

Qualitative research has a wide range of approaches and methodologies such as grounded theory, phenomenology, ethnography, narrative research and case study, but they describe all types having a focus on natural settings, an interest in meanings, perspectives and understandings, an emphasis on the process and involve inducing meaning (28). For

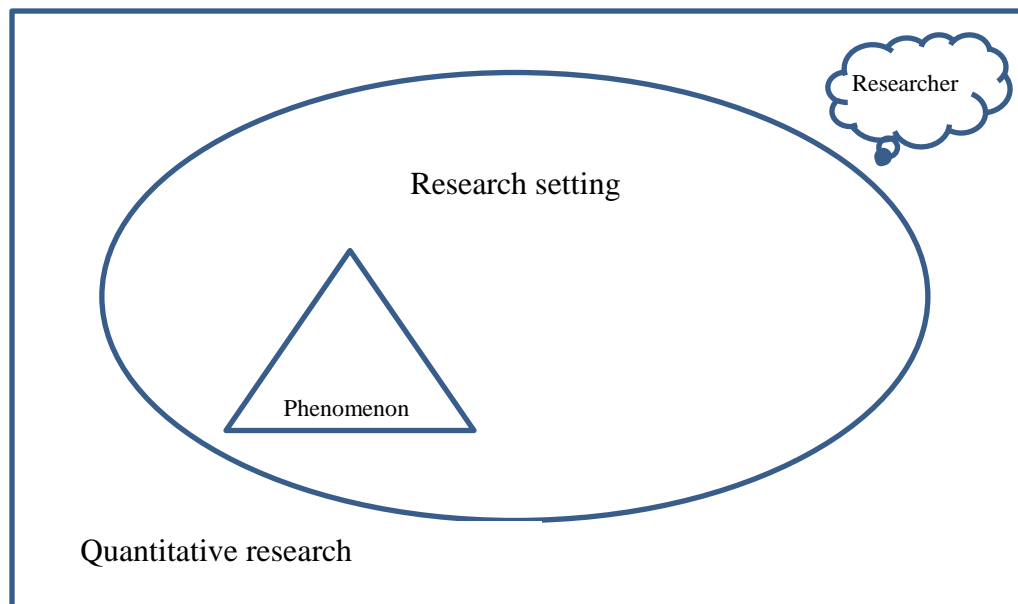
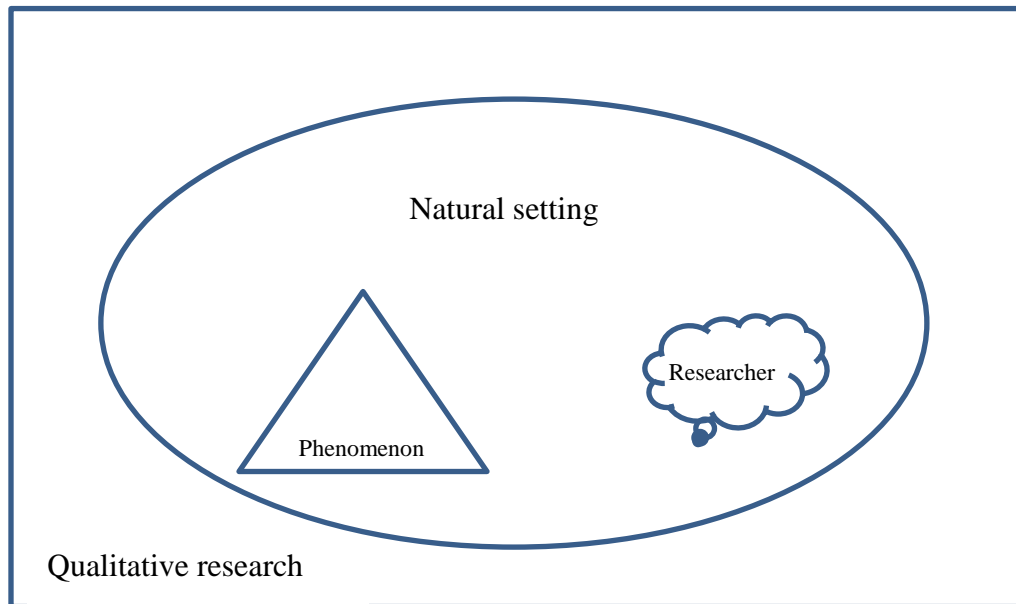
example, quantitative research may look at demographics such as socio-economic background and the prevalence of smoking, but qualitative research would explore what influences certain groups to smoke.

In qualitative research few assumptions as possible are made beforehand and it is about generating possible hypotheses, unlike quantitative research which starts with a hypothesis to test. An example is inductive methodology generally seeking to generate or induce a theory from the data, theory is then said to be 'grounded' in that data as in grounded theory (29). Qualitative research places importance on situations which influence behaviour, and the context in which the behaviour is being studied, with various layers of study and interpretation which can be lengthy to discover deeper meaning that participants attach to behaviour, how they interpret situations and their perspectives. For example, a study by Measor and Woods (30) to attempt to understand how to dissolve gender boundaries at a secondary school by introducing a common curriculum found that boys used cakes as weapons and sewing machines as trains, while girls complained about nasty smells and unisex goggles in physical science. It was by observing the behaviours of the girls and boys in the natural setting of the classrooms whereby the researcher was able to explore what happened and the meaning each gender gave to the subjects on the curriculum; gaining an understanding of the barriers which may be experienced in dissolving gender boundaries. In order to gain deeper meaning, the researcher needs to gain a certain rapport with the subjects, and needs to consider their own influence on the subjects' behaviour. Researchers should also consider the

effects of time and sample across time as the same activity or item could mean different things at different times (28).

Qualitative research is sometimes criticised for not being generalizable although there are examples of where it has been used and debated to determine health care and educational policy (31). For example, Hargreaves (1967) and Lacey (1970) used mainly qualitative methods to study a secondary modern and grammar school respectively and the data they gathered generated the theory of differentiation and polarisation, used in educational policy. They suggested that where pupils were differentiated by ability, then a polarisation of attitudes into pro- and anti-school would occur among them. Some qualitative research does not aim to produce a theory but to understand the quality of social life, including the emotions and complex social interactions which accompany it.

Figure 1: Schematic difference between qualitative and quantitative research methodology.



Methods of qualitative research

Many methods are used in qualitative research such as observation, diaries, interviews and documentary analysis (32, 33).

In observation, the researcher aims to be an unobtrusive observer to the natural situation where the researcher adopts a role in the natural setting, such as a member in a group, or a non-participant observer where the researcher watches the natural situation and tries not to disturb the scene, such as in ethnography (34, 35) .

Interviews can be formal or more casual conversations to explore the participant and their responses (33, 36, 37). The best format in order to minimise the effect of the researcher is the unstructured interview where the researcher has some general ideas or topics but the flow of the interview is dictated by the subject in the natural course of discussion. The researcher tries to appear to be natural rather than someone with the role of research and attention is paid to where the interview happens, the seating arrangements, how the interviewer dresses and the manner of approach in order to keep the setting as natural as possible. The researcher is careful not to appear to be leading along the topic areas, but uses skills and techniques to explore clarity and depth to allow the participant to lead the interview in a non-structured way in order to explore where the participant wants to take the conversation. A disadvantage of the unstructured interview is that it may not cover all aspects which the researcher is interested in (33).

A structured interview is useful when the study is more focussed where the researcher decides the structure of the interview with pre-determined broad topic questions requiring an in depth response from the participant. Semi-structured interviews use some structure but questions which have scope for open-ended answers. Semi-structured interviews are useful to compare responses to themes from different participants or groups (33, 37).

When qualitative research is compared to quantitative research, it is sometimes criticised as lacking vigour in validity, interpretation and bias by the researcher and not being reproducible or generalizable to other situations (38). There are techniques which need to be considered in order to increase the validity of qualitative research (39), i.e. to ensure that the interpretation of findings is real by recognising the researcher's impact on the participant and the natural situation. Such techniques include respondent validation and triangulation. Respondent validation is a technique where the interpretation of findings is given to the participants to judge whether it is an accurate understanding and portrayal after the study is complete (40). Method triangulation uses multiple methods to study an issue to increase accuracy and depth, such as combining structured interviews with observation or questionnaires. Time triangulation studies the issue at different time points, for example before during and after the event. Triangulation of persons might involve consulting with a range of people involved in the issue who may have differing roles where their accounts can then be studied to look for differences. In this study, validity will be attempted using triangulation of method by using semi- structured

interviews and validated questionnaires, time by interviewing at different time points and person by interviewing a number of women in the three groups of route of hysterectomy.

Chapter 2 Return to work: a quantitative analysis.

Introduction

Heavy menstrual bleeding (HMB) is an important cause of ill health in women. Surgical treatment of HMB often follows failed or ineffective medical therapy and the definitive treatment is hysterectomy. This is a major surgical procedure with significant physical and emotional complications as well as economic cost. Resumption of work activities after gynaecological surgery takes much longer than expected, irrespective of the surgical technique used and the severity of the surgery (41-44). Return to work is perceived by patients and increasingly by the health care industry as a highly important outcome and recovery promotion ideas after surgery are not new. There is documented evidence that long periods of sickness absence can result in detrimental personal consequences for the individual in work disability, social exclusion, poorer general health, increased risk of mental health problems and higher mortality (45). An Individual's personal consequence of delayed resumption of normal activities has an impact on the health service resulting in more physician consultations, medical treatment and higher hospital admission rates.

Longer absences are associated with a reduced probability of eventual return to work and subsequent economic and social deprivation (45, 46). Sickness absence is a major public health and economic problem. In 2003, 176 million working days were lost through sickness absence, the cost of which to the economy is enormous. Each absent employee cost their employer £760 per year on average in 2010 through a combination of direct costs in sick pay, lost output and provision of cover. Across the economy as a whole, the

direct costs alone amount to more than £17bn a year and after non-work related injury post-operative recovery time is the second most common cause of absence (47).

Interventions aimed at reducing the post-operative recovery time to resumption of normal activities have a huge potential benefit to individual patients, the health service, Society and the economy. Return to work is a complex concept, influenced not only by the type of surgical procedure but also by a multitude of other variables such as age, education level, income level and type of occupation (23;25) as well as the attitudes and advice given by health care practitioners (25;26). There are reports of immediate ambulation after herniorrhaphy to aid recovery since the 1960's (30) and many since such as studies to investigate return to work rates and factors that influence it in patients undergoing surgical procedures like inguinal hernia repair, coronary artery bypass graft and renal transplant (22-24). There is now evidence that a formal enhanced recovery programme for surgery improves recovery and reduces hospital stay (18) and the ESTReP (Enhanced Surgical Treatment and Recovery Programme) has transformed the way in which colorectal surgery is delivered in the UK (4). Their programme combines known clinical predictors of recovery (such as early feeding after surgery, not using nasogastric tubes or surgical drains) with positive psychological factors such as patient education and health promotion. The ESTReP programme has led to a reduction in the average hospital stay from 9-10 days per patient to 6 days. The authors of the study conclude that this has helped to generate extra bed space to treat more patients, and under the payment by results scheme, has generated more income for their NHS Trusts as well as to help meet 18-week targets (19). They have shown that the programme is cost efficient based on the daily cost on a general or surgical ward of £400, and have gained support from the

Department of Health. The ENHANCE surgery programme is now a national initiative from the NHS Institute of Innovation and Improvement and focuses on patients playing an active role in their recovery (8).

Improving post-operative recovery after a hysterectomy is important to the NHS as it is one of the commonest surgical gynaecological procedures performed; around 40,000 are carried out in the NHS every year (37). Most of these are done on women of working age between 40-50 years (37). Therefore the disease burden on the NHS is high, as is the cost to the economy and society during the post-operative convalescence period.

This study is to identify the baseline return to normal data for women who have had a hysterectomy in our local population at Birmingham Women's Hospital, and to find any factors which may have influenced their return to work.

Aims

This study aimed to establish the baseline data for time of return to work after a hysterectomy and to find any variables such as type of employment and operating consultant which may affect return to work rates following a hysterectomy in our local population at Birmingham Women's Hospital. In particular, data for women who had a hysterectomy for heavy menstrual bleeding was studied. This questionnaire only looked at return to work, not return to normality.

Objectives

Primary research question: For women who have had a hysterectomy for heavy menstrual bleeding, how is time of return to work affected by:

- Type of employment organisation (public or private)
- Type of sick pay (usual, reduced, statutory sick pay, incapacity benefit, none)
- Employment status (full, part time or self-employed)

Responsible consultant **Secondary research questions**

- How is time of return to work related to the patient's perception of whether they returned at the right time, too early or too late?
- Is the patient's perception of their time of return to work influenced by the consultant who operated on them?

Methods

Design

Ethical approval (appendix 1) was gained and a patient information leaflet was sent to all participants (appendix 2). A retrospective structured questionnaire study (appendix 3) which was developed using the standard Department of Work and Pensions questions and variables for sickness pay and employment status. In particular, we were interested to see if there was an association with whether there was further loss of income if women were self-employed or if they did not have any sickness pay cover. The questionnaire was piloted on 3 women in a benign gynaecology clinic waiting room to ensure construct

validity. There were no standard questionnaires known of which we could utilise to answer the research questions for this section.

Study sample

This was a study of women who had a hysterectomy at the Birmingham Women's Hospital over a 12 month period from January 2008-2009. A total of 150 women were identified as having had a hysterectomy using clinical coding systems during this time period for total abdominal hysterectomy, vaginal hysterectomy, laparoscopic assisted hysterectomy and subtotal hysterectomy. The participant information letter (appendix 2), and questionnaire (appendix 3) was posted to the home addresses of all women along with an invitation letter (appendix 3). Responses were then stratified and analysed for women who had a hysterectomy for heavy menstrual bleeding in order to reduce confounders in recovery such as carcinoma; which is known to have more prolonged recovery due to the disease process. Other benign conditions such as endometriosis may have differences in recovery as well associated with the increased pain and surgical complexity associated with the disease per se.

Procedure

The questionnaire was mailed to women at their home address which was identified from hospital databases. A stamped addressed envelope was included for return post. A reminder letter and questionnaire was sent around 3 weeks later.

Analysis

Data from completed questionnaires was analysed using IBM SPSS v16 © by MS. Data was analysed by descriptive statistics of frequency and means. Data distributions were visually examined for normality using histograms. Scatter plots were drawn to explore patterns between time of return to work and type of incapacity benefit, type of employment contract, public or private sector employment and consultant gynaecologist under whose care the surgery was performed. Differences in mean time back to work with the type of employing organisation (private or public) were tested using an independent-samples T-Test. The relationships between time of return to work and employment status (full, part time or self-employed) and type of sick pay were explored by analysis of variance (ANOVA). If significant differences were found between groups, post hoc testing and tests of multiple comparison were performed.

Ethical considerations

Ethical approval was gained from Black Country Research Ethics committee (09/H1202/66) (Appendix 17) and sponsorship from UoB (Appendix 1).

Results

A response rate of 53% was achieved (80/150). Of the respondents, 15 women did work and only 1 did not return to work after her hysterectomy (table 2.1). Of the women who did work, 16 women worked in a private organisation (11 full time, 3 part time, 2 self-employed) and 40 worked in a public organisation (21 full time, 19 part time). During their convalescence, the total number of women who received incapacity benefit as their main source of income was 2, statutory sick pay (SSP) was 12, a reduced income from

their employer was 3 and their usual pay was 35. One woman did not receive any income and 2 women did not answer this question.

**Results for data on women who had a hysterectomy for heavy menstrual bleeding
(Table 2.1)**

Data was split to include only those women who had a hysterectomy for heavy menstrual bleeding. There were a total of 63 women in this group of whom 55 returned to work. Of those who did not return to work, 1 woman had retired, 3 who were unemployed and 4 who did not answer this question. Women in this group were in full time employment in 42.5% of cases, part time in 24% and self-employed in 1.5%. The mean time for return to normality was 11.6 weeks (SD 4.84, table 2.1). Most of these women felt that they had returned to work at the right time (49%) with 15% feeling they had returned too early and only 1.8% feeling they could have returned earlier than they did. For this group of women, 43% received their usual pay while they were on sick leave, 16% received statutory sick pay only, 4% received reduced pay from their employer, and 1.8% received incapacity benefit.

i) Return to work and organisation type

Table 2.2 shows the mean time of return to work according to whether the patient worked for a private (n=16) or public (n=40) organisation. An ANOVA did not show a significant difference between mean time of return to work and public organisation and private organisation $F 0.165$ $p = 0.686$.

ii) Return to work and type of sick pay

Most women received their usual pay during their recovery, but a lower proportion of women received any category of sick pay if they worked for a private organisation (table 2.3). An ANOVA was conducted to explore the impact of type of sick pay received on when patients returned to work (RTW) after a hysterectomy measured in weeks. Type of sick pay was categorised as usual pay, reduced pay, statutory sick pay (SSP), incapacity benefit and no pay (table 2.4). There was no statistically significant difference at the $p < 0.05$ level in the RTW time for the type of sick pay. $F(2, 50) = 0.187$, $P = 0.48$.

iii) Return to work and employment status

An ANOVA was conducted to explore the impact of employment status on when patients returned to work (RTW) after a hysterectomy, measured in weeks. Employment status was categorised as full time, part time and self-employed. There was no statistically significant difference in the RTW time for the type of sick pay.

$F(2, 52) = 0.76$, $P = 0.59$

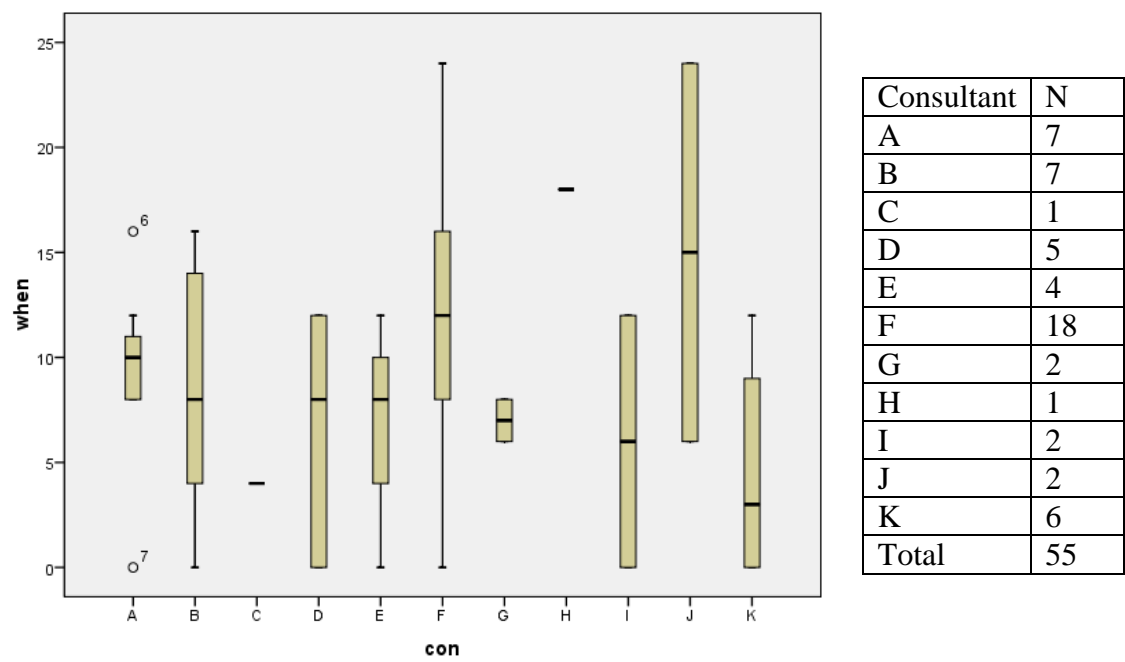
As none of the above variables had a significant effect on RTW, no further statistical tests (such as multiple comparison and post hoc tests) were carried out.

iv) Mean time of return to work and operating consultant

The mean time that patients went back to work according to the consultant who operated on them is shown in figure 2.1 and table 2.5.

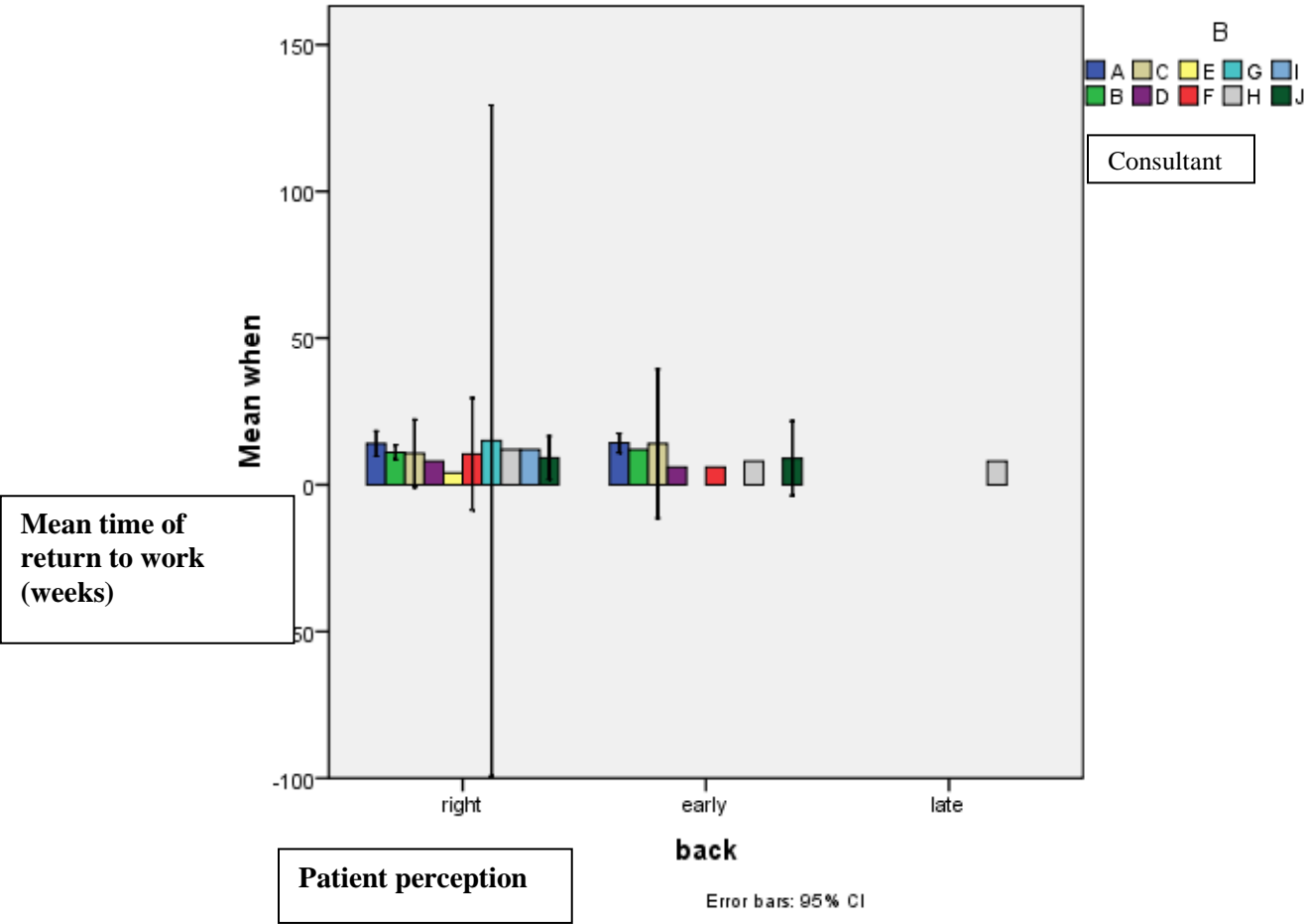
An ANOVA was conducted to explore the impact of consultant on when patients returned to work (RTW) after a hysterectomy measured in weeks. There was no statistically significant difference at the $p < 0.05$ level in the RTW time for the type of sick pay $F(2, 1.087)$, $P = 0.38$.

Figure 2.1: Box plot of return to work time by operating consultant



The influence of operating consultant on patient perception of time of return to work. Figure 2.2 shows patient perception of return to work, actual mean time of return to work and the consultant who operated on them. For most consultants, patients felt they returned to work about the right time or too early. There was no pattern for any particular consultant suggesting that in this cohort, there was no obvious influence of the operating consultant on the patient's perception of time to return to work.

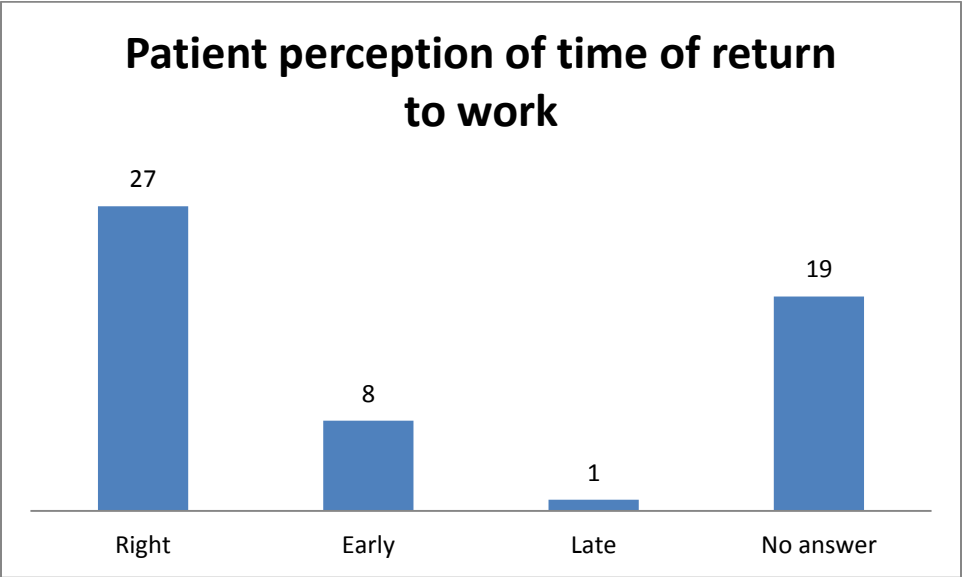
Figure 2.2: Perception of return to work, actual mean time of return to work and operating consultant.



v) Patient perception of return to work and actual mean time of return.

There were no differences in the meantime return to work and whether the patient perceived their return time to be about right, too early or too late (figure 2.3).

Figure 2.3: Patient perception of return to work and actual mean time of return to work.



Discussion

Return to work is a complex concept influenced by not only the disease and type of surgery, but by socioeconomic factors and attitudes of patients and health care workers. It is encouraging from this survey that most women return back to normal after a hysterectomy. This study does not show any differences in when women return to work in relation to the type of incapacity benefit they receive, the type of employment contract they have or whether they work in the private or public sector. However, the numbers in the study are currently too small to be able to detect a difference if it exists, especially for the self-employed versus employed group. There were no real differences in time of return to work and the consultant under whose care the hysterectomy was performed. This may be due to a difference in the type of hysterectomy they had (laparoscopic, vaginal or abdominal) and a difference in the advice about recovery given by each consultant. A larger sample size in a future study will help to confirm whether this difference is statistically significant. Return to work after different routes of hysterectomy was not measured in this survey but other surveys of laparoscopic surgery have shown a positive association with laparoscopic approaches (49). There is no published data to compare the results from our study at BWH to other hospitals for return to work.

Other studies have demonstrated factors which are associated with return to work and have been compared in a literature review for cancer survivors (50). Positive associations included positive reactions of work colleagues and patient reaction to the disease and treatment. Negative associations with return to work included a lack of discussion with health care professionals. Counselling and giving patients realistic expectations pre-operatively and during recovery are therefore important in nurturing a positive attitude for return to work. This review did not find any association with return to work and income or education. There will be specific factors in cancer survivors which cannot be extrapolated to surgery for benign conditions, but pre-operative patient preparation has been shown to be important in other conditions such as laparoscopic cholecystectomy (51), inguinal hernia repair (44) and coronary artery bypass graft (52). These studies did

find a difference in return to work with age, education level, income and type of occupation.

Table 2.1: Return to work after hysterectomy for heavy menstrual bleeding.

Number of women returned to work	87% (55/63)
Reasons for not returning	
Retired	1
Unemployed	3
No answer	4
Full time employment	42.5% (27/63)
Part time employment	24% (15/63)
Self-employed	1.5% (1/63)
Mean time of return to work	11.6 weeks (SD 4.84)
Opinion of return to work	
Right time	49% (27/55)
Too early	15% (8/55)
Too late	1.8% (1/55)
No answer	35% (19/55)
Type of pay while off sick	
Usual	43% (24/55)
SSP	16% (9/55)
Reduced	4% (2/55)
Incapacity	
Benefit	1.8% (1/55)

Table 2.2: Mean time back to work according to the type of organisation.

Type of organisation	Number	Mean time back to work (weeks)	SD time back to work (weeks)
Private	16	11.14	5.53
Public	40	11.76	4.65

Table 2.3: Type of sick pay according to employment in a public or private organisation.

	Total Number	Incapacity (%)	No pay (%)	Reduced pay (%)	SSP (%)	Usual (%)	Not mentioned (%)
Public organisation	40	0	0	2 (10%)	10 (25%)	27 (67.5%)	1 (2.5%)
Private organisation	16	2 (12.5%)	1 (6%)	1 (6%)	2 (12.5%)	8 (50%)	2 (12.5%)

Table 2.4: Mean time back to work according to type of sick pay.

Type of sick pay	Number	Mean time back to work (weeks)	SD Mean time back to work (weeks).
Incapacity benefit	2	16	11
No pay	1	8	
Reduced pay	3	13	2
SSP	12	12	4
Usual pay	35	11	5
Not mentioned	3	6	3

Table 2.5: Mean time of return to work after a hysterectomy with Consultant.

Consultant	Number	Mean time back to work (weeks)	SD time back to work (weeks)
A	6	9	7
B	1	4	
C	30	8	7
D	4	8	7
E	18	12	7
F	2	7	1
G	2	6	8
H	6	4	6

Chapter 3

Health care professionals' beliefs about recovery after hysterectomy: A quantitative cross-sectional study.

Introduction

Doctor-patient communication and physicians' beliefs about efficacy of surgery are known to be important factors when both patients and doctors make treatment decisions for elective surgical procedures (55, 56). Physician factor has been implicated as a source of practice variation (57, 58) which could represent a set of beliefs which have a powerful effect on the behaviour of patients (59). The UK Department of Work and Pensions (DWP) has produced guidance for some surgical procedures but published evidence shows that there is a lack of awareness of them (41). Patients give high importance to the information given to them by health care professionals over other sources and it influences behaviours such as when to return to normal activity. In addition, shared clinical decision making has been shown to improve patient outcomes such as satisfaction and improved functional status (60, 61). However shared clinical decision-making is more difficult than it appears due to divergent perspectives relating to beliefs about health and illness, expectations of medical care, treatment priorities and ways in which information is interpreted (62, 63). As patient behaviour is influenced by the information given to them by health care professionals, and there are variations in their beliefs and advice, there may be a resultant difference in patients' behaviour. Hence study of health care professional beliefs could help us to understand what they think of patient recovery experiences.

Guidance for health care professionals in post-operative recovery has been shown to reduce illness related work absenteeism by several weeks compared to unstructured standard advice (48, 64-70). Well defined postoperative recommendations have been shown to reduce sick leave by several weeks in comparison to standard care given without any structural convalescence recommendations (18, 71-75). In section 1.8 of NICE guidelines for Heavy Menstrual Bleeding (48), the following recommendations are made:

1.8.2 Women offered hysterectomy should have a full discussion of the implication of the surgery before a decision is made. The discussion should include: sexual feelings, fertility impact, bladder function, need for further treatment, treatment complications, the woman's expectations, alternative surgery and psychological impact. [2007]

1.8.5 Individual assessment is essential when deciding the route of hysterectomy. The following factors need to be taken into account:

- *presence of other gynaecological conditions or disease*
- *uterine size*
- *presence and size of uterine fibroids*
- *mobility and descent of the uterus*
- *size and shape of the vagina*
- *history of previous surgery. [2007]*

1.8.6 Taking into account the need for individual assessment, the route of hysterectomy should be considered in the following order: first line vaginal; second line abdominal. [2007]

However detailed recommendations on the resumption of activities are not always provided by medical specialists as a result of the lack of recognised guidelines on the

gradual resumption of activities and because of a lack of knowledge about the physical demands of the patient's job (45, 71, 76). We know there is variation between the advice given by different health care professionals on convalescence from illness which is not evidence based or specific to the type of surgery (77-84) and this will lead to confusion, complications (85) and longer absenteeism for patients. Long periods of sick leave are known to result in work disability, poorer health, an increased risk of mental health disease and mortality (85, 86) Therefore it follows that structured guidance on recovery from specific types of surgery based on evidence and patient experience will provide consistent advice which may lead to better patient satisfaction and expectations and shorter illness related absenteeism.

In this study we will examine the beliefs of health care practitioners upon which their advice to patients is likely based. The advice given to women on recovery after hysterectomy is anecdotal and historical, based on the experience of health care professionals with other patients or on their beliefs. There is substantial variation in the convalescence recommendations given by gynaecologists, general practitioners and occupational physicians (20, 45, 73, 75, 87-89), however we do not know which healthcare professionals patients are more likely to be influenced by. In one study (45), 433 Danish gynaecologists were surveyed about their convalescence recommendations after a vaginal repair procedure for prolapse. Post-operative stay ranged from 1 to 7 days and the recommended sick leave was 2 to 12 weeks with a median of 6 weeks for women with heavy lifting work. The recommended time for commencement of sexual intercourse was 0 to 12 weeks with a median of 4 weeks. The recommended range of

time for non-strenuous activity was 0 to 24 weeks. These differences could not be explained by demographic differences between gynaecologists. Studies have looked at the educational and informational needs of hysterectomy patients (73, 74, 90) and the quality and management of written information given to patients undergoing hysterectomy was evaluated as poor quality and unsuited to patients' needs in NICE guidance 2007 (48). These guidelines also addressed treatment options, indications for surgery and type of surgery, but not return to normality. In a consensus of surgical experts, a reference guide of 4 to 6 weeks after a total abdominal hysterectomy and 2 to 4 weeks after a vaginal hysterectomy has been proposed for recovery (91). More recently an expert multidisciplinary group in Holland made recommendations of 3-4 weeks for laparoscopic hysterectomy, 4 weeks for vaginal hysterectomy and 6 weeks for an abdominal hysterectomy (92) after a modified Delphi Study of 5 gynaecologists, 2 general practitioners, 5 occupational physicians and a representative sample of 63 medical doctor.

Aim:

To explore the beliefs and current practices of UK gynaecologists, South Birmingham PCT general practitioners and local gynaecology nurses in counselling patients before and after hysterectomy.

The following questions were addressed:

- What proportion of health care professionals are aware of the NICE guidelines for Heavy Menstrual Bleeding
- What are the current practices of different health care professionals?

- Health care professional opinions on what influences the practices and beliefs of different health care professionals?
- What advice do different health care professionals give to women after a hysterectomy through the abdominal, vaginal and laparoscopic routes?
- Is there a difference in the above questions for Gynaecologists, General Practitioners and gynaecology nurses?
- What are the beliefs and practices for UK Gynaecologists in the different regions?

Study design.

A cross sectional structured questionnaire study for each health care professional group (UK Gynaecologists, South Birmingham PCT General Practitioners, Gynaecology nursing staff Birmingham Women's Hospital).

Methods

Study sample

There were three sample groups to this study: UK Gynaecologists, South Birmingham Primary Care Trust General Practitioners (SBPCT GPs) and Gynaecology Nursing staff at Birmingham Women's Hospital (BWH). Contact details of UK gynaecologists were sourced from the Royal College of Obstetricians and Gynaecologists database, SBPCT GP details were sourced from SBPCT databases and practice managers and details for BWH Nursing staff was obtained from the Gynaecology Directorate at the hospital. BWH nurses were chosen as there were no databases available for UK or regional gynaecology nurses which we could access. An information sheet and invitation letter was sent to all participants (appendix 4,5).

Measures (appendices 6-8).

The questionnaires were developed using standard measures from SF36 questionnaire as well as to answer the objectives. The questionnaire was divided into three sections asking questions about the health care professional, their usual practice and about their usual counselling to patients. All the questionnaires asked about awareness of National Guidelines for the management of Heavy Menstrual Bleeding (48), whether the health care professional performs or looks after women who have had a hysterectomy by the abdominal, vaginal or laparoscopic routes, and what would influence the routine practice of the professional. The counselling section asked how the health care professional would counsel patients about recovery. This included inpatient stay, length of time they would

advise care would be needed for at home, and when certain physical activities could be performed. These physical activities were taken from the physical functioning subscale of the SF36. SF-36 is a multi-purpose, generic, non-disease targeted health survey which measures functional health and wellbeing. The SF36 has been shown to be both reliable and valid in psychometric evaluation (93, 94).

The questionnaires were piloted on 3 health care professionals and research colleagues from each group to test for understanding. They were adapted for each group to take into account their role in the recovery process, although the bulk of the questionnaire was the same. Items which varied for example was to ask general practitioners about the common complications symptoms they may see such as constipation as this is unlikely to have presented to hospital and therefore gynaecology nurses and gynaecologists may not have as much of an idea about its prevalence. The SF36 questions for recovery were the same in all three questionnaires. Gynaecologists were asked if their practice of choice of surgery route and follow up appointment is based mostly on local, National or personal experience. This question was not relevant for nurses or general practitioners as they would not be making those decisions.

Procedure

Each questionnaire was accompanied with an explanation of the study and its use towards a Doctorate of Medicine (MD) thesis (appendix 9) and invitation letter emailed to participate in the study (appendix 5) with. An email of returned completed questionnaire was taken as participant consent. Questionnaires were sent by electronic-mail using a Survey Monkey link on an Outlook email (appendix 6-8).

Ethical considerations.

Ethical approval was gained from Black Country Research Ethics committee (09/H1202/66). Research and Development approval was gained from Birmingham Women's Hospital Foundation Trust and South Birmingham PCT. Approval of the questionnaires and study was also gained from the Royal College of Obstetricians and Gynaecologists.

Analysis

Descriptive analysis via surveymonkey.co.uk was used to gain an understanding of current practices and beliefs.

ResultsUK Gynaecologists

There were a total of 2600 members and fellows on the RCOG database sent to us. Of these, 1090 were consultants who currently practiced in gynaecology. Questionnaires were emailed to these 1090 with a single reminder. There were 120 emails which were undeliverable due to incorrect email addresses and an overall response rate of 39% (378/970) was achieved.

South Birmingham PCT General Practitioners

A total of 291 questionnaires were mailed out to GP practices with a single reminder. Unfortunately only 1 GP replied and therefore this data was not analysed despite reminders.

Nursing staff at Birmingham Women's Hospital

A total number of 40 questionnaires were sent with a response rate of 43% (18/40) after 1 reminder.

UK Gynaecologists

A total of 378 questionnaires were returned. Figure 3.1 shows the regional distribution of responses. There is good representation from all regions of the UK and Northern Ireland.

Most respondents were in a senior position with 71% of the respondents in a consultant, staff grade or post certificate of completion of training (CCT) grade.

There was a spread in time of experience in their grade from 41% being in their grade for over 10 years and 23% between 1 to 2 years.

The vast majority of gynaecologists performed abdominal (99%) and vaginal (93%) hysterectomies with only 35% reporting that they perform laparoscopic hysterectomies (figure 3.2).

When asking about their practice, 97% of gynaecologists reported that they are aware of the NICE Guidelines on Heavy Menstrual Bleeding, but only 22% reported that they would follow NICE recommendations in surgical route of hysterectomy if there were no other clinical indication.

Most (78%) gynaecologists reported that they would decide on hysterectomy route according to their personal confidence in performing the procedure as opposed to NICE. Most UK gynaecologists offer a follow up appointment after hysterectomy (60%). The decision for follow up is based on personal belief/experience for 55%, unit policy for 41% and on evidence for only 4%.

Recovery advice

Inpatient days (table 3.1)

There was a large spread in the recovery advice after a hysterectomy given by UK gynaecologists. Most (46%,) of gynaecologists advised 3 inpatient days routinely after an abdominal hysterectomy, but 15% advised 2 days, 28% advised 4 days and 10% advised 5 to 7 days. One gynaecologist advised less than 1 inpatient day routinely and 1 advised more than 7 days. After a vaginal hysterectomy, 40% routinely advised 2 inpatient days but 37% advised 4 days. There was one gynaecologist who advised less than day, 16% advised 1 day only, 4% advised 4 days and 2% advised 5 to 7 days. Routine advice on inpatient days after a laparoscopic hysterectomy was 2 days in 41% of gynaecologists and 2 days in 40%. There were 8% who routinely advised less than 1 inpatient day, 10% who advised 3 days and 1% who advised 5 to seven days.

Table 3.1:

Number of inpatient days gynaecologists would routinely advise after different types of hysterectomy

Type of hysterectomy	Number of days advised routinely for inpatient stay (% and frequency of response)						
	Less than 1	1	2	3	4	5-7	More than 7
Abdominal	0.5%	0	15.2%	46%	28.3%	9.6%	0.5%
	(1)		(30)	(91)	(56)	(19)	(1)
Vaginal	0.5%	16.2%	39.9%	37.4%	4%	2%	0
	(1)	(32)	(79)	(74)	(8)	(4)	
Laparoscopic	8.1%	41.4%	39.4%	10.1%	0	1%	0
	(16)	(82)	(78)	(20)		(2)	

Number of weeks for care at home (table 3.2).

After an abdominal hysterectomy, 33% of UK gynaecologists would advise patients that they need 5-6 weeks of care at home. Again there was wide variation in advice ranging from 1.5% advising only 1 week of care and 5% advising 11 to 12 weeks of care. For a vaginal hysterectomy, 21% would advise 1 to 2 weeks of care at home but almost as many (19%) would advise 3 to 4 weeks of care. This advice ranged from 6% advising 1 week and 3% advising 11 to 12 weeks of care. After a laparoscopic hysterectomy, 29% advised 1 to 2 weeks of care at home. The range was 13% advising only 1 week of care and 1.5% advising 11 to 12 weeks.

Table 3.2:

Advice about number of weeks patients will need care at home after different types of hysterectomy.

Type	Routine advice for number of weeks patients will need care at home												
	(% and frequency of response)												
	0-1	1-2	2-3	3-4	4-5	5-6	6-7	7-8	8-9	9-10	10-11	11-12	>12
Abdominal	1.5%	10.3	12.9	16.5	3.1%	33%	9.3	6.7	1	0.5	0	5.2	0
	(3)	%	%	%	(6)	(64)	%	%	%	%		%	
		(20)	(25)	(32)			(18)	(13)	(2)	(1)		(10)	
Vaginal	6.2%	20.6	12.4	18.6	11.3	17.5	5.7	4.6	0	0.5	0	2.6	0
	(12)	%	%	%	%	%	%	%		%		%	
		(40)	(24)	(36)	(22)	(34)	(11)	(9)		(1)		(5)	
Lap	13.4%	28.9	16%	17.5	8.8%	7.7%	4.1	2.1	0	0	1.5	0	
	26	%	(31)	%	(17)	(15)	%	%			%		
		(56)		(34)			(8)	(4)			(3)		

Advice regarding physical recovery after different types of hysterectomy

Abdominal hysterectomy (table 3.3)

After an abdominal hysterectomy 21% of UK gynaecologists would advise 5-6 weeks post operation before vigorous activity such as running, lifting heavy objects and participating in strenuous sports. The range was 1% advising 4 weeks and 6% advising more than 16 weeks. For moderate activities such as moving a table, pushing a vacuum cleaner, bowling and playing golf, 25% advised 5 to 6 weeks after an abdominal hysterectomy and 23% advised 6 to 7 weeks. The range was 0.5% advising 1 week and 0.5% advising more than 16 weeks. Advice was varied for lifting or carrying groceries with 28% advising 4 weeks with a range of 1% advising 1 week and 0.5% advising more than 16 weeks. For climbing several flights of stairs, 24% advised 4 weeks with a range of 1% advising 1 week and 1% advising more than 16 weeks. There was more consensus on the advice for climbing one flight of stairs with 52% advising 1 week; however the 0.5% reported advising 14-16 weeks. For bending, kneeling and stooping, 38% advised 1 week with a range up to 0.5% advising more than 16 weeks. The advice for walking more than a mile was 26% advising 4 weeks with a range of 1.5% advising 1 week and 0.5% advising more than 16 weeks, whereas the advice for walking several hundred yards was 21% advising 1 week, 27% advising 2 weeks and 23% advising 4 weeks. The range for advice for walking several hundred yards was up to 0.5% again advising over 16 weeks for this activity. There was better consensus for the advice for walking one hundred yards with 45.5% advising 1 week (up to 1% advising 12-14 weeks) and for bathing or dressing where 82% advised 1 week (up to 0.5% advising 10-12 weeks).

Table 3.3: Advice after an abdominal hysterectomy for physical recovery

Activity	Number of weeks												
	1	2	3	4	5-6	6-7	7-8	8-9	9-10	10-12	12-14	14-16	>16
Vigorous	0	0	0.5%	1%	15.7	21.2	8.6	3.5	3.5	27.3	12.1	0.5	6.1
*1			1	2	%	%	%	%	%	%	%	%	%
					31	42	17	7	7	54	24	1	12
Moderate	0.5%	2%	7.1%	18.7	24.7	23.2	6.1	7.1	4%	4%	1.5%	0.5	0.5
*2	1	4	14	%	%	%	%	%	8	8	3	%	%
				37	49	46	12	14				1	1
Lifting or	1%	4.5%	10.6	27.8	22.7	18.2	5.1	3%	1%	3.5%	1%	1%	0.5
Carrying	2	9	%	%	%	%	%	6	2	7	2	2	%
groceries			21	55	45	36	10						1
Climbing	9.1%	18.7	14.1	24.2	15.2	10.6	1.5	0.5	0	2.5%	1%	1.5	1%
several	18	%	%	%	%	%	%	%		5	2	%	2
flights of		37	28	48	30	21	3	1				3	
stairs													
Climbing	52%	28.8	6.1%	3%	1.5%	0.5%	0.5	0	0.5	1%	0	0.5	0.0
one flight	103	%	12	6	3	1	%		%	2		%	
of stairs		57					1		1			1	
Bending,	37.9	32.3	5.6%	13.6	5.1%	3%	1%	0	0	1%	0	0	0.5
kneeling,	%	%	11	%	10	6	2			2			%
stooping	75	64		27									1
Walking	1.5%	16.2	11.1	26.3	17.7	15.2	3%	2%	2%	3%	1%	0.5	0.5
more than	3	%	%	%	%	%	6	4	4	6	2	%	%
1 mile		32	22	52	35	30						1	1
Walking	21.2	26.8	12.1	23.2	9.6%	3%	0.5	1.5	0	1%	0	0.5	0.5
several	%	%	%	%	19	6	%	%		2		%	%
hundred	42	53	24	46			1	3				1	1
yards													
Walking	45.5	28.3	12.1	7.1%	4%	0.5%	0.5	0	0	1%	1%	0	0
1 hundred	%	%	%	14	8	1	%			2	2		
yard	90	56	24				1						
Bathing/	81.8	13.1	2.5%	1.5%	0	0	0.5	0	0	0.5%	0	0	0
dressing	%	%	5	3			%			1			
yourself	162	26					1						

*1 Running, lifting heavy objects, strenuous sports *2 Moving a table, pushing a

vacuum cleaner, bowling or playing golf.

Vaginal hysterectomy (table 3.4)

After a vaginal hysterectomy 20% of UK gynaecologists would advise 5-6 weeks post operation and 20% would advise 6-7 weeks before vigorous activity such as running, lifting heavy objects and participating in strenuous sports. The range was 1% advising 2 weeks and 4.5% advising more than 16 weeks. For moderate activities such as moving a table, pushing a vacuum cleaner, bowling and playing golf, 25% advised 5 to 6 weeks and 21% advised 4 weeks. The range was 1.5% advising 1 week and 0.5% advising more than 16 weeks. Advice was varied for lifting or carrying groceries with 30%% advising 4 weeks with a range of 4.5% advising 1 week and 0.5% advising more than 16 weeks. For climbing several flights of stairs, 24% advised 4 weeks with a range of 19%% advising 1 week and 0.5% advising more than 16 weeks. There was more consensus on the advice for climbing one flight of stairs with 67% advising 1 week; however the 0.5% reported advising 14-16 weeks. For bending, kneeling and stooping, 58% advised 1 week with a range up to 2.5% advising 10 to 12 weeks. The advice for walking more than a mile was 28% advising 4 weeks with a range of 12% advising 1 week and 0.5% advising more than 16 weeks, whereas the advice for walking several hundred yards was 34% advising 1 week and 25% advising 2 weeks. The range for advice for walking several hundred yards was up to 0.5% again advising over 16 weeks for this activity. There was better consensus for the advice for walking one hundred yards with 64% advising 1 week (up to 0.5% advising 10-12 weeks) and for bathing or dressing where 89% advised 1 week (up to 0.5% advising 9-10 weeks).

Table 3.4: Advice after a vaginal hysterectomy for physical recovery

*1 Running, lifting heavy objects, strenuous sports *2 Moving a table, pushing a vacuum cleaner, bowling
or playing golf

Activity	Number of weeks												
	1	2	3	4	5-6	6-7	7-8	8-9	9-10	10-12	12-14	14-16	>16
Vigorous *1	0	15	1.5%	10.1%	20.2%	20.2%	8.6%	5.1%	3.5%	18.7%	5.6%	1%	4.5%
		2	3	20	40	40	17	10	7	37	11	2	9
Moderate *2	1.5%	10.6%	11.1%	20.7%	24.7%	15.7%	5.1%	4%	2.5%	2%	1%	0.5%	0.5%
	3	21	22	41	49	31	10	8	5	4	2	1	1
Lifting or Carrying groceries	4.5%	13.6%	9.6%	30.3%	14.1%	16.2%	4.5%	1%	0.5%	2%	1%	0.5%	0.5%
	9	27	19	60	28	32	9	2	1	4	2	1	1
Climbing several flights of stairs	19.2%	22.2%	11.1%	23.7%	11.6%	6.1%	0.5%	0.5%	0	2.5%	0.5%	1.5%	0.5%
	38	44	22	47	23	12	1	1		5	1	3	1
Climbing one flight of stairs	67.2%	17.7%	4.5%	4.5%	2%	1.5%	0.5%	0.5%	0	1%	0	0.5%	0
	133	35	9	9	4	3	1	1		2		1	
Bending, kneeling, stooping	57.6%	22.2%	3%	9.1%	4%	1%	0.5%	0	0	2.5%	0	0	0
	114	44	6	18	8	2	1			5			
Walking more than 1 mile	12.1%	18.7%	11.6%	28.3%	12.1%	8.6%	3.5%	1%	0	2.5%	1%	0	0.5%
	24	37	23	56	24	17	7	2		5	2		1
Walking several hundred yards	34.3%	25.3%	9.6%	20.7%	5.1%	1.5%	0.5%	0	1%	0	0.5%	0	0
	68	50	19	41	10	3	1		2		1		
Walking 1 hundred yards	64.1%	18.2%	7.1%	4.5%	3%	1%	0.5%	0	0	0.5%	0	0	0
	127	36	14	9	6	2	1			1			
Bathing/ dressing yourself	89.4%	8.6%	0.5%	0.5%	0	0	0.5%	0	0	0.5%	0	0	0
	177	17	1	1			1			1			

Laparoscopic hysterectomy (table 3.5)

After a laparoscopic hysterectomy 21% of UK gynaecologists would advise 4 weeks post operation, 17% would advise 5 to 6 weeks and 17% 6-7 weeks before vigorous activity such as running, lifting heavy objects and participating in strenuous sports. The range was 2% advising 1 week and 2.5% advising more than 16 weeks. For moderate activities such as moving a table, pushing a vacuum cleaner, bowling and playing golf, 25% advised 4 weeks. The range was 5.6% advising 1 week and 1% advising more than 16 weeks. Advice was varied for lifting or carrying groceries with 29% advising 4 weeks with a range of 11% advising 1 week and 1% advising more than 16 weeks. For climbing several flights of stairs, 27% advised 1 week and 27% advised 2 weeks. However, 1% advised more than 16 weeks. There was better consensus on the advice for climbing one flight of stairs with 73% advising 1 week; however the 1.5% reported advising more than 16 weeks. For bending, kneeling and stooping, 63% advised 1 week with a range up to 1% advising more than 16 weeks. The advice for walking more than a mile was 25% advising 4 weeks, 21% advising 1 week and 23% 2 weeks. Again 1% reported advising more than 16 weeks. The advice for walking several hundred yards was 42% advising 1 week with a range up to 1.5% again advising over 16 weeks for this activity. Again there was better consensus for the advice for walking one hundred yards with 70% advising 1 week (up to 1% advising over 16 weeks) and for bathing or dressing where 91% advised 1 week (up to 1% advising over 16 weeks).

Table 3.5: Advice after a laparoscopic hysterectomy for physical recovery

Activity	Number of weeks												
	1	2	3	4	5-6	6-7	7-8	8-9	9-10	10-12	12-14	14-16	>16
Vigorous ^{*1}	2%	3.5%	7.1%	21.2%	16.7%	16.7%	9.6%	4.5%	2.5%	12.6%	0	1%	2.5%
	4	7	14	42	33	33	19	9	5	25		2	5
Moderate ^{*2}	5.6%	21.2%	11.6%	24.7%	15.2%	13.1%	1.5%	1.5%	0.5%	4%	0	0	1%
	11	42	23	49	30	26	3	3	2	2			2
Lifting or Carrying groceries	11.1%	22.2%	12.1%	28.8%	9.6%	8.1%	2%	2%	0.5%	2%	0	0.5%	0.5%
	22	44	24	57	19	16	4	4	1	4		1	1
Climbing several flights of stairs	26.8%	26.8%	12.6%	20.2%	5.6%	2%	0	0.5%	0	3.5%	0	1%	1%
	53	53	25	40	11	4		1		7		2	2
Climbing one flight of stairs	73.2%	15.7%	3.5%	2%	1.5%	0.5%	0	0	0	1.5%	0	0.5%	1.5%
	145	31	7	4	3	1				3		1	3
Bending, kneeling, stooping	65.2%	19.7%	3%	5.1%	2.5%	0.5%	1%	0	0.5%	1.5%	0	0	1%
	129	39	6	10	5	1	2		1	2			2
Walking more than 1 mile	20.7%	22.7%	13.6%	25.3%	8.1%	4%	0.5%	0.5%	2.5%	1.5%	0	0	1%
	41	45	27	50	16	8	1	1	3	3			2
Walking several hundred yards	41.9%	27.8%	12.6%	10.6%	2%	1%	0	1%	1%	0.5%	0	0	1.5%
	83	55	25	21	4	2		2	2	1			3
Walking 1 hundred yard	70.2%	15.7%	6.6%	2%	1.5%	0.5%	0.5%	0.5%	1%	0.5%	0	0	1%
	139	31	13	4	3	1	1	1	2	1			2
Bathing/dressing yourself	90.9%	3.5%	1%	1.5%	0	0.5%	0.5%	0	0.5%	0.5%	0	0	1%
	180	7	2	3		1	1		1	1			2

*1 Running, lifting heavy objects, strenuous sports *2 Moving a table, pushing a

vacuum cleaner, bowling or playing golf.

Variations in advice

We were not able to demonstrate regional variations in whether gynaecologists choose route of hysterectomy according to NICE guidance or personal confidence (figure 3.3), or according to specialist grade or years of experience in that grade (figure 3.4). A follow up appointment seemed to be made routinely more often in London and least in the North East and North West (figure 3.5). Consultants seemed to be less likely to make a routine follow up appointment (71%) and trainees in years 6-7 appeared to be most likely to offer them (figure 3.6). Consultants mainly followed personal belief in this (75%), although 48% of consultants reported their choice as unit policy (figure 3.7). A lower proportion of gynaecologists made a routine follow up appointment if they were more experienced in their grade (44%), and of these, 44% followed personal belief and only 23% reported following evidence (figure 3.8). These differences may be as a result of variations in local health care set ups and commissioning agreements.

Figure 3.1:

Regional distribution of responses (Ireland is Northern Ireland)

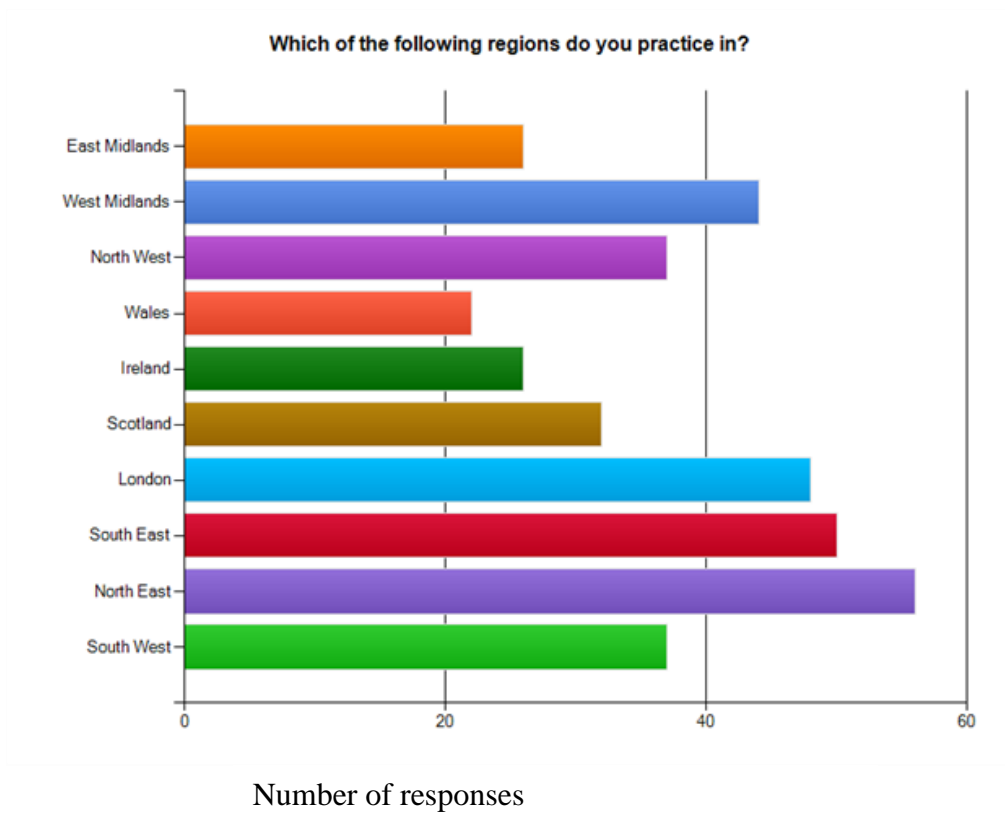


Figure 3.2:

Proportion of gynaecologists who perform types of hysterectomy

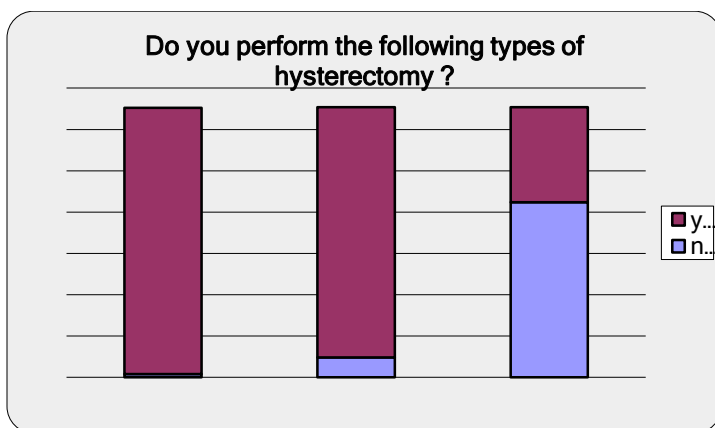


Figure 3.3:

Regional variation in decision for route of hysterectomy

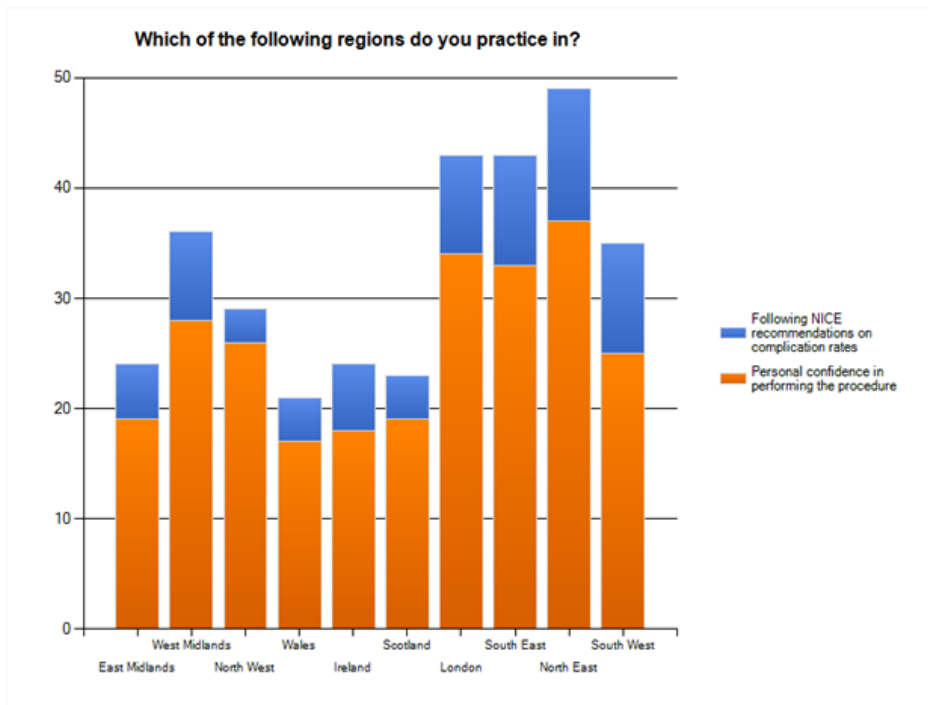


Figure 3.4:

Experience level and decision for route of hysterectomy

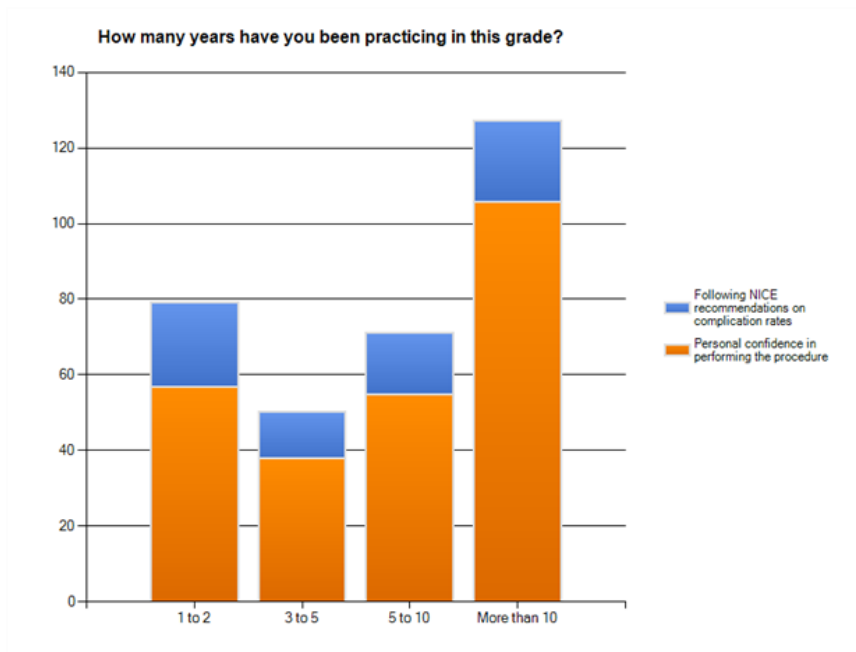


Figure 3.5:

Regional variations in offering a routine follow up appointment

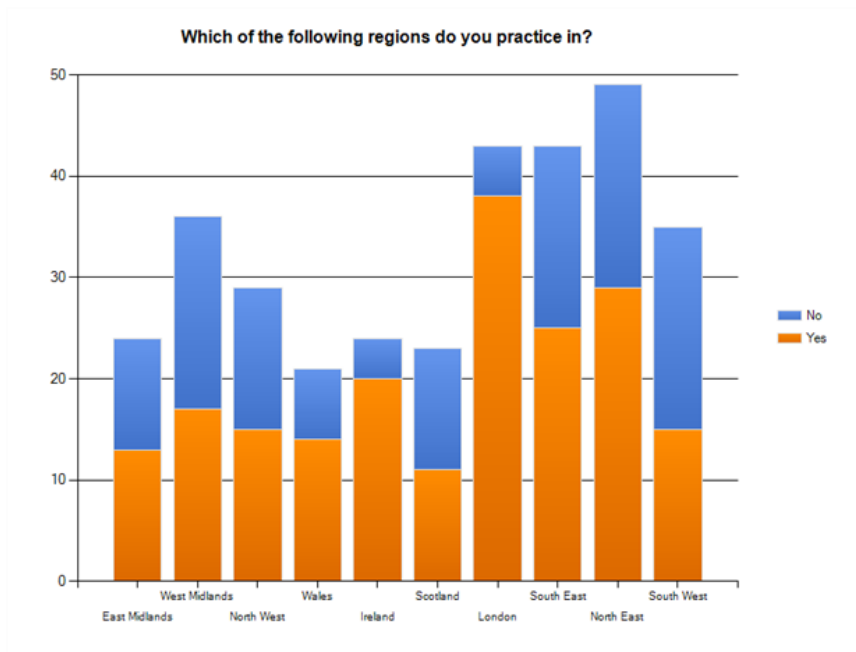


Figure 3.6:

Variations in follow up appointment and grade

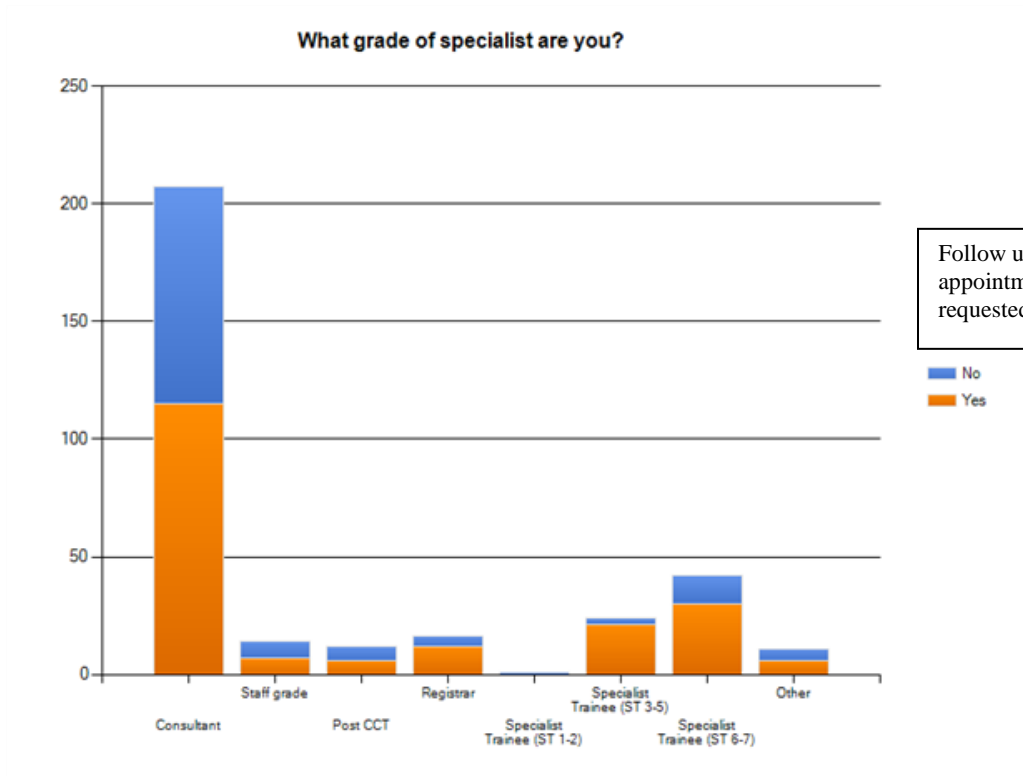


Figure 3.7:

Regional variations in reasons to offer routine follow up appointment

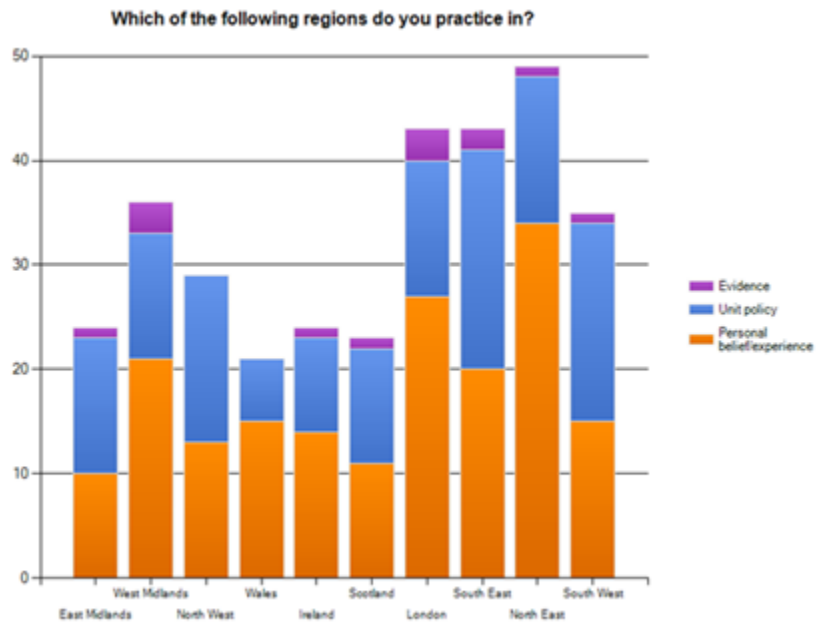
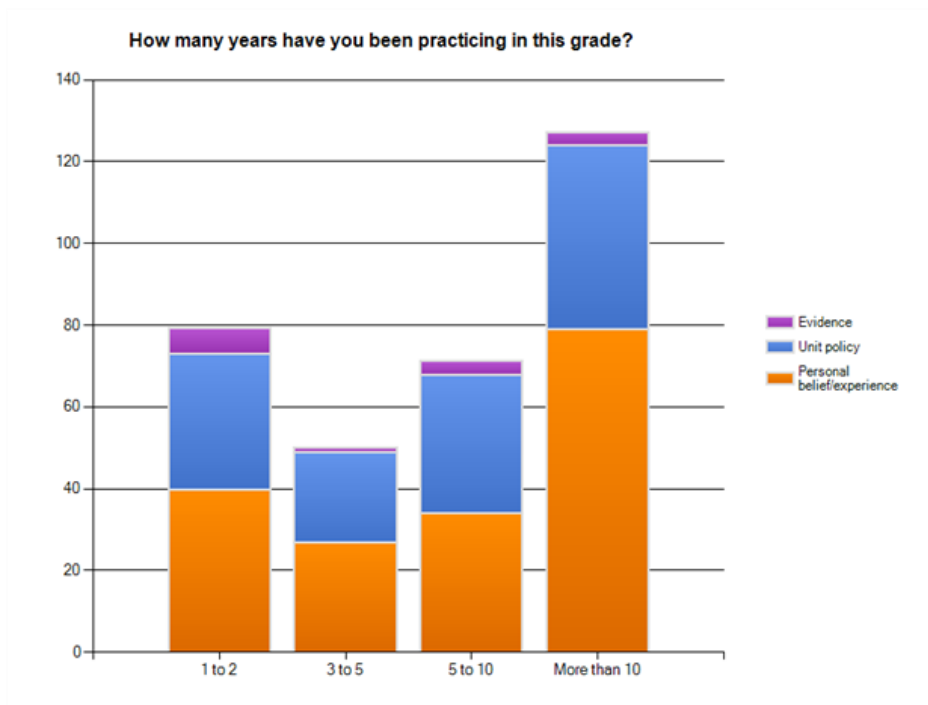


Figure 3.8:

Variations in decision making for offering a follow up appointment and experience in grade



Results Gynaecology nurses Birmingham Women's Hospital

There were 18 responses out of 40 after a single reminder (43%). The mean number of years of experience was 11.88 years (3-30). Statistical comparisons were not made between the UK gynaecologists and BWH nurses due to the small number of responses from nurses.

In-patient days after each type of hysterectomy (table 3.6).

After a total abdominal hysterectomy, two thirds of nurses would advise a stay of 4 to 6 days, with the remaining one third advising 2 to 3 days. After a vaginal hysterectomy, there was more consensus with 94.5% advising 2 to 3 days. After a laparoscopic hysterectomy, only 28% of nurses would advise a 1 day stay in hospital with the remainder advising 2 to 3 days.

Table 3.6:

How would you routinely counsel your patients regarding numbers of postoperative days stay in hospital?

	Number of days % (number of responses) 0-1	Number of days % (number of responses) 2-3	Number of days % (number of responses) 4-6	Number of days % (number of responses) 7-12
Abdominal hysterectomy	0	39% (7)	61% (11)	0
Vaginal hysterectomy	0	94.6% (17)	4.5% (1)	0
Laparoscopic hysterectomy	28% (5)	72% (13)	0	0

Number of weeks of care at home (table 3.7)

The majority of nurses (79%) advised between 2 to 6 weeks care at after an abdominal hysterectomy, this was also similar after a vaginal hysterectomy where 89% also advised 2 to 6 weeks. After a laparoscopic hysterectomy, most nurses (79%) advised 0 to 3 weeks of care at home.

Table 3.7:

How many weeks of care at home would you advice?

Route	Weeks			
	0-1	2-3	4-6	7-12
hysterectomy	% (number of responses)	% (number of responses)	% (number of responses)	% (number of responses)
Abdominal hysterectomy	4.5% (1)	39% (7)	44% (8)	11% (2)
Vaginal hysterectomy	11% (2)	50% (9)	39% (7)	0
Laparoscopic hysterectomy	39% (7)	44% (8)	17% (3)	0

Advice after an abdominal hysterectomy for physical recovery.

All nurses felt that vigorous activity was only advised after 6 weeks and most felt that this was the same for moderate activity (94%) and lifting (65.5%). The majority of nurses would advise climbing one flight of stairs (83%), bending, kneeling and stooping (61%) walking a hundred yards (83%) and bathing and dressing (94%) after 1 week. Half of all nurses would advise walking several hundred yards after 1 week with only 17% advising to wait more than 2 weeks, whereas 90% of nurses would advise waiting more than 2 weeks to walk more than 1 mile. A third of nurses advised climbing several flights of stairs after 1 completed week, but a third advised to wait until after 6 completed weeks (table 3.8).

Table 3.8:

Number of weeks for advice after abdominal hysterectomy for physical recovery

Activity	Weeks (% responses)									
	1	2	3	4	5-6	6-7	8-9	12-14	>16	Don't know
Vigorous ^{*1}	0	0	0	0	0	50% 9	11% 2	22% 4	4.5% 1	11% 2
Moderate ^{*2}	0	0	0	4.5% 1	0	83% 15	0	0	4.5% 1	4.5% 1
Lifting or Carrying groceries	0	0	4.5% 1	22% 4	0	61% 11	0	0	0	4.5% 1
Climbing several flights of stairs	33% 6	22% 4	0	11% 2	4.5% 1	11% 2	0	4.5% 1	0	17% 3
Climbing one flight of stairs	83% 15	11% 2	0	0	0	0	0	0	0	4.5% 1
Bending, kneeling, stooping	61% 11	11% 2	0	11% 2	0	11% 2	0	0	0	4.5% 1
Walking more than 1 mile	4.5% 1	4.5% 1	22% 4	33% 6	0	17% 3	0	0	4.5% 1	11% 2
Walking several hundred yards	50% 9	66% 6	0	0	0	0	0	0	0	17% 3
Walking 1 hundred yard	83% 15	4.5% 1	4.5% 1	0	0	0	0	0	0	4.5% 1
Bathing/dressing yourself	94% 17	0	0	0	0	0	0	0	0	4.5% 1

Advice after a vaginal hysterectomy: physical recovery (table 3.9)

After a vaginal hysterectomy, most nurses advised waiting until after 6 weeks before vigorous activity (89%), and 66% advised lifting only after 4 weeks. For climbing stairs, 89% advised being able to climb one flight and 39% advised climbing several flights in a week. The majority of nurses advised bending (67%), walking 1 hundred yards (83%) and bathing and dressing (94%) in 1 week.

Table 3.9: Number of weeks for advice after vaginal hysterectomy: physical recovery.

Activity	Weeks (% number of responses)								
	1	2	3	4	6-7	8-9	12-14	More 16	Don't know
Vigorous ^{*1}	0	0	4.5% 1	4,5% 1	50% 9	4.5% 1	17% 3	4.5% 1	11% 2
Moderate ^{*2}	0	0	0	28% 5	61% 11	0	0	4.5% 1	4.5% 1
Lifting or Carrying groceries	0	11% 2	4.5% 1	4.5% 1	55% 10	0	0	0	4.5% 1
Climbing several flights of stairs	39% 7	28% 5	17% 3	4.5% 1	11% 2	0	4.5% 1	0	17% 3
Climbing one flight of stairs	89% 16	4.5% 1	0	0	0	0	0	0	4.5% 1
Bending, kneeling, stooping	67% 12	4.5% 1	0	22% 4	0	0	0	0	4.5% 1
Walking more than 1 mile	11% 2	17% 3	11% 2	28% 5	17% 3	0	0	4.5% 1	11% 2
Walking several hundred yards	50% 9	33% 6	0	0	0	0	0	0	17% 3
Walking 1 hundred yard	83% 15	4.5% 1	4.5% 1	0	0	0	0	0	4.5% 1
Bathing/ dressing yourself	94% 17	0	0	0	0	0	0	0	4.5% 1

Advice after laparoscopic hysterectomy: physical recovery (table 3.10)

No nurses advised waiting after 7 weeks for any of the physical recovery activities.

Thirty nine percent felt that vigorous activity and 44% felt that moderate activity could be advised by 2 weeks. The majority felt that climbing a flight of stairs (94%), bending (81.5%), walking several hundred yards (77%), walking 1 hundred yards (94%) and bathing and dressing (94%) could be advised by 1 week.

Table 3.10 Number of weeks for advice after laparoscopic hysterectomy: physical recovery.

Activity	Weeks (% number of responses)							
	Less 1	1	2	3	4	5-6	6-7	Don't know
Vigorous ^{*1}	0	11% 2	28% 5	0	11% 2	4.5% 1	33% 6	4.5% 1
Moderate ^{*2}	0	22% 4	22% 4	0	22% 4	0	28% 5	4.5% 1
Lifting or Carrying groceries	0	22% 4	28% 5	4.5% 1	17% 3	0	22% 4	4.5% 1
Climbing several flights of stairs	0	50% 9	33% 6	0	0	0	0	17% 3
Climbing one flight of stairs	0	94% 17	0	0	0	0	0	4.5% 1
Bending, kneeling, stooping	4.5% 1	77% 14	4.5% 1	4.5% 1	4.5% 1	0	0	4.5% 1
Walking more than 1 mile	0	28% 5	33% 6	0	11% 2	0	11% 2	11% 2
Walking several hundred yards	0	77% 14	4.5% 1	0	0	0	0	17% 3
Walking 1 hundred yard	0	94% 17	0	0	0	0	0	4.5% 1
Bathing/ dressing yourself	0	94% 17	0	0	0	0	0	4.5% 1

Discussion

This survey represents the practice and beliefs of 378 gynaecologists representing all regions in the UK and a small number of gynaecology nurses in one unit. The main findings from this study are that there is great variance between the advice UK gynaecologists and nurses would give after all types of hysterectomy. There is better consensus for activities which are appropriate within the first week such as walking a few hundred yards, bathing and dressing and climbing one flight of stairs. This may be due to the fact that all these activities are usually achieved before discharge from hospital and so gynaecologists and nurses are familiar with these milestones. Longer term recovery advice is surprisingly varied, suggesting that UK gynaecologists and nurses are less familiar or confident about this. There seems to be a difference in the type of advice given between the three different routes of hysterectomy such as vigorous activity. Most UK gynaecologists would advise 4 weeks after a laparoscopic hysterectomy, 5 to 6 weeks after a vaginal and 10 to 12 weeks after an abdominal hysterectomy. Advice for other activities such as moderate activities was more similar (most recommending 5 to 6 weeks for abdominal and vaginal and 4 weeks for laparoscopic) and no difference in the advice to walk more than a mile between route of hysterectomy (4 weeks for all routes). The advice given by gynaecology nurses is similar for all types of hysterectomy route for immediate postoperative activities, but is lower for longer term recovery activities for the laparoscopic route. There is surprisingly less difference in longer term recovery advice after an abdominal or vaginal hysterectomy for heavy menstrual bleeding. Limitations of this study include differences in the sample demographics for gynaecologists and nurses. It would have been useful to have been able to compare responses between these groups.

A better study design would have been to have UK gynaecology nurses; which could have been via a survey to gynaecology units in the UK. Another limitation is that gynaecology nurses were not asked if they follow NICE guidelines in their approach to counselling, again making it difficult to then compare or draw meaningful conclusions.

The results from this survey differ to one carried out in the Netherlands (95) with UK gynaecologists advising longer convalescence in all categories of activities. In the Netherlands survey, a Delphi technique was used to come to a consensus of opinion from a total of 12 experts (5 gynaecologists, 2 GPs and 5 occupational physicians). In a Delphi technique, the survey options are reduced according to the most popular responses and the survey is re-issued a number of times repeating this step at each issue. In this way, participants are forced to choose and prioritise between the reduced options until a consensus is reached. The UK survey is a one off survey with all options available. Therefore, the difference in methodology of survey may explain the differences. In the Netherlands survey, advice for recovery was shorter in all categories and for all routes of hysterectomy. For light work, the UK opinion was 4 to 7 weeks (55% of cases) for laparoscopic hysterectomy whereas the Netherlands consensus was 1 week, for moderate activity UK was 4 weeks (25%) versus 2 weeks and for heavy activities UK was 4 weeks (29%) versus 3 weeks. For abdominal hysterectomy, UK opinion on light activities was 4 weeks (28%) versus 2 weeks in Netherlands, for moderate activities it was 5 to 7 weeks (53%) against 3 to 4 weeks and for heavy activities it was 5 to 6 weeks (21%). For vaginal hysterectomy, the UK opinion on light activities was 4 weeks (30%) compared to 2 weeks, for moderate activities it was 4 to 6 weeks (46%) compared to 3 weeks and for

heavy activities it was 5 to 7 weeks as compared to 4 weeks for the Netherlands consensus. The difference in results may be explained by the differences in methodology and slightly different examples of heavy, moderate and light activities. It may be that a Delphi study on our UK gynaecologists would find a different consensus of opinion due to the methodology of a Delphi where multiple surveys are sent around to participants based on the results of the previous survey. In this way, the participants of the survey would be presented with fewer options in each survey round and are then asked to choose their most appropriate response for the focussed options (so in a way are forced to choose between options that they may not have originally considered). However, the larger number of gynaecologists in our survey would suggest that this survey is more representative of gynaecologist opinion and practice and patients may be influenced by differing advice. If recovery, especially long term is influenced mainly by health care professionals, then conflicting advice to patients is likely to cause confusion and frustration. It may also have an impact on the economy if patients are advised to stay off work for longer than they need to or conversely, be contributing to problems if patients are advised to return to work too soon. It seems that the published advantage of faster recovery from laparoscopic or vaginal routes is not conveyed to UK patients, and hence may be reflected in longer and similar actual recovery times for all routes. NICE guidance advice using a vaginal approach as first line, then abdominal as second line taking into account the need for individual assessment (59). Although there is National NICE Guidance in recommendations for the route for hysterectomy, most UK gynaecologists use their own experience and confidence to decide on the surgery despite knowing of the evidence, and do not follow the pattern of guidance set out by NICE. The

reason for this may be due to the quality of the evidence upon which the recommendations in guidelines have been made. If it is poor quality or based on consensus opinion, some health care practitioners may choose to follow their own experience and beliefs. This finding is in keeping with the published literature for difficulties in implementing research findings.

This survey also gives information on the current hysterectomy practice in the UK at the time of the survey, with only 35% performing laparoscopic hysterectomies. Conversely, a similar and high proportion (99 and 93%) of UK gynaecologists perform abdominal and vaginal hysterectomies.

There is also a culture of offering a routine follow up appointment after surgery (60%), which seems to be derived from personal belief or experience (55%) as well as unit policy (41%). This is interesting in a climate of efficiency with commissioners trying to reduce follow up rates in secondary and tertiary centres. It may be that NHS Trusts and individual gynaecologists will be asked to reduce their post-operative follow up rates and it is likely that Trusts will not get remunerated for unnecessary follow up appointments. In my opinion, unless there are specific concerns, most post-operative follow ups can be managed in primary care as long as there has been good communication from the hospital to the GP. At the post-operative hospital visit, the majority of women will have recovered, but will have had to take time out of their schedules to travel to hospital and wait to be seen to be *told* they have recovered. The post-operative visit is an opportunity to answer patient questions and review any complications. However, we should aim to communicate with our GP colleagues so that this follow up is not necessary. If there are

specific concerns, then those patients should be re-referred. Complications requiring re-presentation to the hospital will still be monitored on hospital statistics, but it seems inefficient to see patients in a clinic to gain information on minor complications e.g. urinary tract infections. Other more innovative ways of checking on patient progress should be found such as telephone consultations by nursing staff at recovery time points which are agreed to be important for each type of surgery. This is an area where Trusts can increase their efficiency with relative ease without compromising the quality of care.

A limitation to this study is the lack of responses from GPs which leaves open the question of what GP beliefs are, whether they will give appropriate or consistent advice. It may be that GPs are too busy in responding to research questionnaires, which raises the question of whether they would have the time or resources to arrange follow up visits after surgery. Unfortunately, I was not able to get any feedback from GPs so I was not able to ask why they did not respond to the survey, it may be that they were not interested in the survey, in research or it may have been that the methodology of emailing the survey was flawed. At the time of the survey email, the local GPs were going through a transition in email addresses from individual practices to NHS.net accounts. It is therefore likely that a number of emails did not reach the GPs and I did not receive any response to indicate that there was a change in email address. A similar issue occurred when our trust changed to NHS.net where a number of emails were lost. I came to know after the completion of the study that there had been a technical issue with GP email addresses and this cross over and this may have affected the email survey. Similar to the Dutch Delphi study, other health care professionals such as physiotherapists are not

usually involved in the recovery process for hysterectomy and therefore were not part of this survey.

Conclusion

UK gynaecologists and gynaecology nurses at Birmingham Women's hospital give variable advice on recovery from all route of hysterectomy. There is more consensus in opinion for activities which would be expected to be accomplished while still an inpatient. It is reassuring that there are no differences in opinion according to different regions, but there is variation by experience and grade, which is what we expected to see. Furthermore, there was variation by personal belief as opposed to by national or local policy. As patients are greatly influenced by the advice given by health care professionals, particularly by doctors (50, 51) it is important to provide consistent advice based on evidence and actual patient experience.

Chapter 4: Experiences of women who have a hysterectomy; a qualitative interview study

Introduction

The experiences which women go through during and after a hysterectomy have been discussed for many years. In December 1982, an article in the Guardian: Every Woman's Right to Know (Perry C) stated:

'Having a hysterectomy is an emotional as well as a physical operation, it is to do with being a woman, it is to do with conception and sex; the children you've had or won't be able to have'.

Better counselling and preparation for hysterectomy can improve the way women cope and recover from the surgery. The hysterectomy often comes at a time in their lives when they are also facing other personal crises such as going through the menopause, children growing up and changes in the roles they perceive themselves in. A post hysterectomy syndrome has been described where depression is the primary component, although there is a wide range of reported incidence for the syndrome of 4-70% (96, 97) but overall the estimate of depression is 2 to 4 times higher than the general population, peaks at 2 years post-surgery and lasts for 2 to 3 times longer than in age matched controls who have had other surgeries.

We know that information patients are given has an effect on their experience (76) and that patient expectations influences patient satisfaction of medical treatment (64). Dissatisfied patients are less likely to comply with medical advice, default from follow up appointments and show less improvement in symptoms than satisfied patients (65). Patients seek information from various sources including the internet, where a search for the term hysterectomy presents 7,160,000 links including a variety of web pages, chat rooms, patient's forums and patient support groups. One such patient website is Hysterosisters Online (<http://www.hysterosisters.com>), which describes itself as a social support site for women who are undergoing the experience of a hysterectomy. This website published the results of a survey in which they found that patients sought information and advice more than emotional support or self-esteem ($p<0.01$) (98). Despite the huge array of published literature there is concern regarding the provision of information for women undergoing treatment for heavy menstrual bleeding, particularly in the recovery phase (48, 99, 100) and women and their partners still express wishes for more information (101). There have been specific questions regarding the reliability and accuracy of information on the internet and its effect on the relationship between the patient and health care professional (79, 80).

At Birmingham women's Hospital, women are prepared for hysterectomy by trained pre-operative nurses during a pre-operative appointment. At this appointment, the nurse talks about the hysterectomy and provides written information in the form of leaflets. The details cover what will happen on the day, when to arrive and where, what to pack and bring in with them as well as fasting information. Recovery information includes

discussion and leaflets about pain, movement and self-help such as how to get out of bed easier and breathing techniques to ease pain. Recovery advice once discharged includes symptoms to look out for in case of complications, driving advice and general advice on how long the recovery might take. There is also advice about the effect of surgery on sexual function and when it is safe to resume sexual intercourse. If the patient asks for more detailed advice about any aspect in particular, the nurse gives individualised information based on their own experience. The patient is encouraged to bring the leaflets into hospital with them as a reference guide. This process is the same for both benign and non-benign disease. There is not published literature on how this process varies from

Most published studies of patient experience and belief ask retrospective questions about clinical outcomes from hysterectomy such as effectiveness and safety; or look at a single time points in the patient journey such as length of stay, and satisfaction at time of questionnaire (102, 103). Some studies acknowledge these limitations and recommend longer follow up periods for recovery outcomes (104). A more recent published study has looked at 3 and 12 month recovery from hysterectomy; however it focused on chronic pain only and did not consider other recovery outcomes or experiences. A literature review of qualitative studies for enhanced recovery highlighted how patients required additional support to be motivated in recovery during times of symptoms such as pain, nausea and weakness. This study concluded that patients still required more consistency in information pre and post-operatively in order to feel confident about symptom management (107). In this qualitative study, we have followed women through from the pre-operative period to three months after the hysterectomy in order to gain a longitudinal

understanding of the women's experiences of hysterectomy by the vaginal, laparoscopic and abdominal routes.

We know that recovery is affected by the underlying pathology of the specific disease process as well as co-morbidity. In breast cancer, a study reported on the experiences for young women taking into consideration their unique situation of cancer diagnosis at early age (108), and similarly for recovery 6 months after colorectal cancer surgery (109). These studies showed how individuals required specific support in their recovery because of their diagnosis. In order to reduce the differences in experiences due to underlying variation from disease process, this study is limited to recovery from hysterectomy for heavy menstrual bleeding in order to reduce the confounding effect of disease process on recovery such as cancer.

Aim:

To explore in depth the beliefs, longitudinal experiences and expectations of women who have a hysterectomy for heavy menstrual bleeding through the vaginal, abdominal and laparoscopic routes.

Study design

A longitudinal semi-structured interview study of women who are having a hysterectomy at the Birmingham Women's Hospital through the abdominal, vaginal or laparoscopic routes.

Methods

Sample

We recruited women who were on the waiting list to have a hysterectomy for heavy menstrual bleeding by the abdominal, vaginal or laparoscopic routes at Birmingham Women's Hospital. An estimated target sample of ten women from each hysterectomy group was set. We did not delineate between whether women were planned to or had their ovaries removed as the study was mainly looking at route of surgery. A total number of 26 women were finally recruited which represented 10 from the abdominal route, 7 from the vaginal route and 9 from the laparoscopic route. Recruitment was stopped at this stage as no new themes were emerging from the interviews. All women were identified from Birmingham Women's Hospital elective waiting list databases and they were invited to join the study during their pre-operation visit to the hospital, which was usually between 1 and 4 weeks before surgery where consent for the study was taken after an explanation of the study with the participant information leaflet (appendix 9).

Measures

Semi-structured interview topic guides were drawn up for the pre-surgery interview and the post-surgery one (appendices 10,11). They were tested in interviews to 3 lay people and patient volunteers to ensure that they were coherent.

Procedure

Participants were telephoned to arrange convenient times for the interviews. Some participants opted to have the interview at home, whilst others came to the Birmingham Women's Hospital. If the interview was at the hospital, a private room without disturbance was arranged each time. If the researcher went to a participant's home for the interview, the details of the venue were left with the research secretary who was included in the ethical application. The researcher telephoned on arrival and departure from the interview venue for safety. The researcher informed participants that she would be carrying identification, and produced this at each interview. Before the start of the interview, the consent was again confirmed. The consent form included options for doing and recording the interview, completing questionnaires and the participant's General Practitioner being informed of their participation in the study (appendix 10 and 11). Once the participant agreed to continue, the microphone was tested and each interview was carried out as set out in the interview topic guide. Interviews were transcribed by the research team secretary and checked by Dr M Shehmar by reading the transcripts while listening to the interviews. Interviews were undertaken pre-surgery and at around 3 months post-surgery. Interviews before surgery focussed on preparation for recovery and

expectations of recovery at 1 week, 1 month, 2 months and 3 months post-surgery.

Interviews post-surgery focused on actual experiences.

Analysis

Interviews were analysed by thematic analysis (33) in order to gain an understanding of the common themes which emerged from the study, which is a more feasible method rather than reporting each experience comment made. As the themes were identified through interrogation of the interview transcript by the researcher retrospectively and not in the natural setting of the recovery (i.e. not alongside the patients in their recovery environments), the validated methodology of thematic analysis was chosen to meet the aims of the study rather than other methods described in chapter 1b. The methodology of thematic analysis used a framework as described below was followed:

Steps of thematic analysis (84).

Step 1: Familiarization of the data

The interviews were read and listened to multiple times to become familiar with their content.

Step 2: Thematic analysis

Common themes were identified in the interviews and were labelled as codes (table 4.1).

Step 3: Indexing

All interviews were then read again in detail and the codes were applied to each line of the interview transcript manually.

Step 4: Charting

Charts of summaries of the data arranged by codes were made to see across themes and the whole data set. Summaries were then referenced back to the whole data set.

Step 5: Mapping and interpretation.

Where possible, inferences were made by looking at relationships between the codes by using diagrams and tables.

Table 4.1 Codes of analysis

Theme	Subtheme	Code
Preparation		1
	Practical preparation	1.1
	Emotional preparation	1.2
	Physical preparation	1.3
	Experiential preparation	1.4
	Informational preparation	1.5
	Social preparation	1.6
	Cognitive preparation	1.7
	Sexual preparation	1.8
Decision making		2
	Type of hysterectomy	2.1
Expectations		3
	Hospital stay	3.1
	Recovery	3.2
	Influences	3.3
	Support	3.4
Recovery		4
	1 week	4.1
	Emotional	4.1.1
	Physical	4.1.2
	Behavioural	4.1.3
	Social	4.1.4
	Sexual	4.1.5
	4 weeks	4.2
	Emotional	4.2.1
	Physical	4.2.2
	Behavioural	4.2.3
	Social	4.2.4
	Sexual	4.2.5
	8 weeks	4.3
	Emotional	4.3.1
	Physical	4.3.2
	Behavioural	4.3.3
	Social	4.3.4
	Sexual	4.3.4
	12 weeks	4.4
	Emotional	4.4.1
	Physical	4.4.2
	Behavioural	4.4.3
	Social	4.4.4
	Sexual	4.4.5

Theme	Subtheme	Code
Thoughts of surgery		5
	Negative	5.1
	Positive	5.2
Others attitude		6
	Partner	6.1
	Children	6.2
	Family	6.3
	Friends	6.4
Effects		7
	Of surgery	7.1
	Illness	7.2
Experiences		8
	Of surgery	8.1
	of hospital stay	8.2
Recovery		9
	1 week	9.1
	Emotional	9.1.1
	Physical	9.1.2
	Behavioural	9.1.2
	Social	9.1.3
	Sexual	9.1.4
	4 weeks	9.2
	Emotional	9.2.1
	Physical	9.2.2
	Behavioural	9.2.3
	Social	9.2.4
	Sexual	9.2.5
	8 weeks	9.3
	Emotional	9.3.1
	Physical	9.3.2
	Behavioural	9.3.3
	Social	9.3.4
	Sexual	9.3.5
	12 weeks	9.4
	Emotional	9.4.1
	Physical	9.4.2
	Behavioural	9.4.3
	Social	9.4.4
	Sexual	9.4.5
Experiences vs. expectations		10
	As expected	10.1
	Positive	10.2
	Negative	10.3

Results

Sample characteristics

All participants were women who had a hysterectomy for heavy menstrual bleeding as a primary diagnosis. They underwent a total abdominal hysterectomy vaginal hysterectomy or laparoscopic hysterectomy. The participants had a range of occupations involving varying degrees of physical activity including stocking heavy items as a bar worker, teacher, housing officer, carer, nurse, retired and house wife.

Qualitative interview thematic analysis.

Part I Preparation Pre-surgery

Information

All groups talked about the variety of information available as books, leaflets and on the internet. They all felt that there was a large amount of information and that it was difficult to sift through to find what was useful. They talked about how some of the information made them worry, including videos on you tube showing the whole procedure from start to finish, and sites where they felt it was easy to try and self-diagnose to their own detriment. Some participants talked about buying the wrong books and some about trying to distract themselves from the information. There was no difference in the three routes of surgery and the laparoscopic hysterectomy (LH) hysterectomy group were no less concerned.

TAH group

IB06- Bought a book, *'And I think I will bin it. It's not my sort of book. But it tells you week one what you can do, week two, week three you know right up to week 6. Em, and it's just you can't do anything, according to this book. But obviously it depends on how you are.'*

IB18- *'I try not to think about IT'* – preparing going into hospital.

LH group

IB16 *'There is so much help on the internet now for people to self-diagnose a bit which is a bit of a worry for the doctors I suppose cos you talk yourself into having lots of things can't you? But em I think I used to be a nurse anyway and I was pretty clear headed where I was looking. I knew exactly what my symptoms were'*.

IB22 was having mixed feelings – *'It's I've been on the internet and I kind of read about some of the complications and so on. ...and not that I am not confident in the doctors and everything, but in the back of your mind wondering you know is this going to happen to me... You know the fact that you can you can have probably injury to the bladder ...not that I've known anyone that has experienced anything like that but it's just sometimes you stumble over information, that do you more harm than good to be honest'*.

IB22- *'Sometimes you stumble on things on the internet that do you more harm than good to be honest.'* IB22 – Had not intended to go on the internet but her husband asked

something *'and I thought I will try and get some information to explain....and I saw this video on you tube, you know, and it kind of shows you from start to finish what they basically do and it just looks terrifying to be honest'.*

IB22 – A nurse watched a video on YouTube on start to finish of surgery *'I felt better seeing it to be honest.'*

VH group

IB09 *'And having the two kids they keep me busy so I've just been trying to find things to take my mind off it'.*

IB14- Internet , use long words. *' then I thought no I'm not gonna look at this anymore because I am going to frighten myself.....because unless you are a medical person some of the terminology and expressions used could be a little worrying.'*

Practical preparation

A number of participants outlined the practical preparation they had made before their surgery which included child and pet care arrangements, tying up loose ends such as paying bills, completing housework in case they could not do it for a while after surgery and arranging for help with cooking and shopping. This did not differ in the three routes of surgery, and there were examples of this theme in all routes and the responsibilities this age group of women have.

TAH group

IB005 – *‘I’ve got so many animals and that, that I have had to arrange for like neighbours who are gonna be coming in and you know, it’s just like, probably because I’ve got so many, I’ve gotta arrange for them to be fed’.*

IB005 – *‘I live with my husband so he’ll be doing all the day to day things like cooking and things like that.’*

IB01- *‘I have been doing all my windows and changing me curtains and everything because I know I’m not gonna be able to do it.’*

LH group

IB13 – *‘There is people who have offered to come in and help with the kids. And people have offered to come in and do my housework and stuff...I’ve got a good network around me’.*

IB21- plans to look after granddaughter *‘My other daughter is coming to stay here, and em, she is going to get her on the bus, get her dressed you know certain things like that’.*

IB07 *‘I have made arrangements with school, em because of me not driving or anything, they will come and collect him and fetch him back for me...Because there is no plans for single parents with the government to help out with transport’.*

IB16 *‘My sister is a nurse and she has offered to take some time off work to look after me for the first few days anyway...or to help out with the shopping and bits and pieces’.*

IB22 *‘husband is taking 2 weeks off work’.*

IB14 (VH) *‘I have organised that my husband will do the housework and my sister in law’.*

IB14- *'I have tried to get on top of everything. I have washed all the clothes, washed all the bedding, seen to me curtains.'*

Physical preparation

In the abdominal and laparoscopic hysterectomy group, there were examples where participants had talked about trying to improve their fitness before surgery. However, this was not the case with the vaginal hysterectomy group, in fact one participant described how due to her problems she had stopped her fitness regime of dancing as she thought it was making it worse and would wait until after surgery to resume.

IB16 (TAH) *'I had physiotherapy every couple of weeks and I had an exercise plan as well. He has been building up my core muscles'*. Walking and getting fit, tried to lose weight to help with recovery.

IB06 (LH) – Walking to get fit *'I've tried to lose a bit of weight.'*

Emotional preparation

Both the abdominal and laparoscopic group talked about how the surgery had affected their emotions. Some participants had not thought about their emotions and whether they would change and some were quite concerned about how they would emotionally cope with the surgery. One participant talked about the fear of losing her job if she was going to need much time off after her surgery and the financial effect. Some participants saw the hysterectomy as a positive influence on their emotions and that it would lead to a reduction in the stressors in their life.

IB004 (TAH) *'I don't think men understand do they. It's part of you at the end of the day that you are having to give up.'*

IB004 *'His attitude to it is well I'll pick you up and drop you off and I've gotta go to work meself like, you know.'*

IB004 *'He's frightened as well as I am am but they don't show it. Do they. And, em, I'm hoping after everythings done I can get me life back in order because it has been an emotional up and down roundabouts circle'*

IB004 – Fear of effect on lifestyle, although her sisters' have had a hysterectomy, concerned that her life is busier and that she still goes to work when they do not *'And it's just sort of grabbed my life and held it. You know, I've had 10 months off work where I couldn't cope with that'*.

Fear of sickness – IB004 *'I just basically thought, you know I'm gonna lose ma job'*.

Financial strain – IB004 *'As obviously it affects your money..so, now he is doing extra days overtime. He is working 6 days a week.'*

IB16 (LH) *'Emotionally, I haven't really thought about it ..I am just, well it's part of life, you know you've had children...and with the pain I have had over the last year with the amount of problems..I am just looking to see this hopefully resolve....then I can get back on track'*.

Worried about complications – IB22(LH) *‘...the fact that some people get depressed and everything you know. I am just hoping that doesn’t come my way, cos you know, that’s probably something I wouldn’t be able to deal with’.*

Sexual preparation

Some women were concerned about how removal of their ovaries would affect their emotions and the consequences.

IB07 *‘I’m having my ovaries out I should imagine all them strange. A bit like the baby blues...And that’s horrible....Mood swings....Yeah and that’s worrying me really because you shout at your kids don’t you. They suffer’.*

IB005 – *‘They (hormones) are probably going to be a bit all over the place, like. You know, probably weepy and things like this and probably irritable’.*

Cognitive preparation

There were not many participants who spoke about preparing for the loss of their fertility however, there were examples of both apprehension about losing their fertility and philosophical views where a participant saw it as a natural life cycle event.

IB007 (TAH) *'I think it really hits home. ... it is and you can't even think about having any more children'.*

LH *'Well its part of life, you know you've had children. I am 49 tomorrow. I am not gonna have any more children em and with the pain I have had over the year I will be just so happy if it it does resolve the problems that I've got my life because I used to be very fit and active.'*

Some participants did talk about whether they had prepared themselves and their partners for any changes in their sexual lives after the surgery. It seemed that most women would ask their doctors for advice on when it would be safe to continue with their sexual lives, and they felt they needed review first before being confident to resume.

IB22 *'I understand that I can't be sexually active until maybe up to 6 weeks or so. I haven't even spoken to him to be honest. I probably told him at one point that you know definitely I will be unable to do anything like that until you know been seen or reviewed by my doctors'.*

IB24 *'I'm just trying to think what it's going to be like, is everything going to be normal in you know your private life, is everything going to be perfect again?I spoke to him he said just speak to the doctor'.*

One participant assumed it would mark the end of her sexual life, IB10- *'Well I won't have any sex drive.'*

One participant did talk about how she had actively asked the question from the pre-operative nurse, who explained to the participant's satisfaction.

IB007 – *'I asked her (pre-operative nurse) ..you know what happens actually to the sex, sexual side and she explained it all to me. So I know what to expect when it comes down to that. And I said well its not gonna be any different from what it already is really for me'.* (Said she had lost her libido years ago).

It was interesting how many women were reluctant to speak about their sexual preparedness and the most usual answer was that it was not going to make any difference or that it was not a concern to them.

A couple of participants talked about how they had booked activities to look forward to which they believed would aid their recovery by having something to aim towards, such as a 40th birthday party, holidays, booking cinema tickets (IB16), Christmas and Easter celebrations.

Some participants talked about getting mentally prepared for the surgery through positive attitudes or by rationalising and justifying the surgery to bring about an improvement in their lives afterwards.

IB13 'Gotta have it done, that's it isn't it. So carry on the way I was, which is not making me any happier or have it out and we will see'.

IB21 (LH) 'Mentally I'm gonna be fab because I am not gonna have a period anymore and that's it, it's a big thing in my life. I can't go swimming. You know. Can't go out and about'.

Decision making

Participants talked about how they had tried other options to manage their heavy menstrual bleeding before and how they had finally come to the decision of surgery. There was a theme of surgery being seen as a last resort with delays due to their situation excluding surgery as an option at the time. Participants talked about wanting an option which gave them a definitive end to their problems.

IB16 had an ablation before – *'I know that em the NHS does like you to try lots of different options first before you go for a major operation...but because I'm a single parent...em really I would have hoped for the hysterectomy earlier really...and really it has taken so long you know it's a big impact on our lives at the moment..the fact that I am not at work'*.

IB18- *'I've been having heavy periods..I've had em since I was 15..And I had the bilation (ablation) 2 years ago. And that didn't work'*.

IB07 *'I know I've got to do it but because I am on the Prostat (Prostap) injections I haven't had a period now for 3 months, and my iron levels are 14.3, and I feel really good, like I used to feel'*.

IB07 *'I hadn't gone for it before now. I've had other things, I've had the Mirena coil which didn't work. I've had tablets and goodness know what else. I havn't gone for it before now because of the situation with somebody looking after the children..so really I suppose I put myself on the back burner'*.

IB005 – Had the Mirena but had side effect – *‘And once I had it fitted, I started getting really bad dizzy spells...to the point where I would be at work and get this floating feeling in my head and I’d have to hold on to something’.*

IB010- *‘I just feel I’ve suffered for 20 years and I feel like the, the people I’ve spoken to have all said it was the best thing they ever did’.*

IB09 *‘I have also had the coil fitted and had various tablets to try and stem the bleeding. And I know there is a procedure where you can burn the lining of the womb, but to me I have had enough done that has let me down because the hospital has done everything that they thought was right to try and stop it and help. I just think my body needs something final to say that’s it no more’.*

IB16 – Had a failed ablation *‘I don’t think it worked very well for me. I had a lot of pain after it and I was hoping that it would resolve and it didn’t ever resolve.’*

Participants understood that a hysterectomy via any route was major surgery and that they had considered the decision in this light.

IB06 *‘It’s the only guarantee, em because I was offered the ablation ...but the consultant said it was about 30% successful..and I didn’t want to go through that and find that it hadn’t worked. And then of course you go back on the waiting list for everything....I*

know it's a major decision and it's a major operation, but I don't wanna have to go back in 12 months and try something else'.

Sometimes, the decision was influenced by other co-existing problems such as prolapse or ovarian cysts, completion of their family and those affected had an understanding of the rationale and there was evidence of joint decision making with the gynaecologist.

Associated breast cancer in family with HRT after hysterectomy - IB01- *'before when they first told me I was going to have the hysterectomy I didn't want to know. I refused point blank I wasn't gonna have because I've got my aunty who had it done, my mother had it done and obviously they both got breast cancer and that was my main issue'. ...The HRT tablets and that was one of my biggest worries actually'.*

There was no difference with the route of surgery in the reasons given for choosing surgery, and all groups talked about the effect of heavy bleeding on their quality of life and how they saw surgery as a way to improve this.

IB01- *'Because if I arrange to go out with my friends.....and I came on. Full stop I can't go.'*

IB 013 *' I mean I was out shopping one day, came back and just got covered in blood. It's not nice when you have got children here...the reason they decided it was the best solution was, because I had been sterilised 4 years ago'.*

IB21- *'And because I am a carer for my grand-daughter, I need to be on top form really. So the only option is to have a hysterectomy....I am on iron tablets, I am on the pill at my age em I am on tablets to stop the flow and but I have had a thrombosis so all those tablets are just not right for me'.*

IB06 *'Em, its just a necessary evil so to speak. You know my periods have been bad for so long that I just wanna stop the bleeding'.*

Choice of surgical route

In some instances, the participants talked about how the route was determined by their doctors and some of them although they had an understanding of why that route was advised found it was different from what they had hoped for. For the laparoscopic route, the main understanding for this choice seemed to be smaller scars and better recovery.

IB010- *'I was hoping that I wouldn't have to be cut across the stomach...But (consultant name) has said it was too big to do that.'*

IB24 *'Then it won't leave a lot of scars cos as I said before, if your body would be normal, I don't like lots of cutting on your body. So that, he said the keyhole is just a little hole'.*

IB06- *'Well em that wasn't my choice, that was the surgeon's. So hopefully if there are no complications with the keyhole, less invasive, quicker recovery'. Recovery time – single woman dependant on her car and needing to be able to drive quickly to be able to get out of the house'.*

Single parent -IB07 *'Because there is no way I would have gone through with an 8 week recovery thing..because I just couldn't...there's no leeway, you know school they've just gotta be there'.*

IB21 *'The doctor suggested it'. She thought 'Yes great Quick recovery rather than a bigger recovery...you know with the scar across there then it takes you more time to recover. Whereas two little ones I am hoping that I will be up and about quicker.'*

IB16 *'I'm having which one is it now..the laparoscopic hysterectomy. But em, until they look inside they don't know what they are gonna do...but if they can't do the procedure then they will do the abdominal hysterectomy....I am not too happy about having lots of scars on my tummy but there is no other way round it, so you know. And I do heal up pretty quickly...and it's not like I go round showing my tummy all the time...so it's not too bad'.*

Only a few women talked about how they had actively thought about the route they wanted and why.

IB06 *'Thought a lot and looked online for route 'But I think I went a bit too far, You know. Because does it really matter what they are gonna do to me under anaesthetic. I know they are gonna remove my womb which is the whole point of it.'*

Ib16 *'I'm not too happy about having lots of scars on my tummy but there is no other way round it.'*

One participant had changed her mind on the route once reading the information leaflet, and was concerned with her recovery. Furthermore, she was influenced by her mother's experiences.

IB09 After pre op *'Em I signed the consent form for a vaginal hysterectomy but I have read the leaflet....And I'm swayed off that now so I want the abdominal hysterectomy so I see there is a few questions round that and if I can still change'*

When asked why: IB09 *'Em, oh sounds a bit, I am funny about anything coming out like that end.... Em and I know I am gonna be sore if I have the abdominal, sort of on my stomach line and yes I will be sore down there but I think I will be more sore if I have it out of there and I don't like being uncomfortable down there.'*

IB09 *'I don't like being swollen in my vagina area. And that makes me more apprehensive and stressed and I don't know if that will lengthen the recovery time...And my mon had a hysterectomy (abdominal) ..so I've seen how people recover from that....And looking at the two, I think you go with what you know really'.*

Removal of ovaries

Although the number of women who had their ovaries removed was not considered in this study, nor was it balanced in the sample of women interviewed, some participants talked about their understanding and questions around the decision as to whether their ovaries would be removed as well as the hysterectomy.

IB13 – *'I understand that if I keep my ovaries I will go through the change normally and if I don't then I will have to go on HRT'.*

IB007 Did not know where her eggs would go if the ovaries were left in place once the womb was removed *'and then I learnt that you still have the oestrogen hormoneand that you need that for your bones and whatever. And that, you see I didn't know that'.*

IB16 *'The only thing that I am unsure about is the HRT whether I will need that. I mean that's a bit confusing. Because one of my doctors has told me that even if you do need HRT that sometimes it is best for maybe a homeopathic type which is like plant oestrogens. ..Cos it's not clear at the moment 100% what's gonna actually be done on the day'* [removal of ovaries].

One participant talked about how she was finding it difficult to make the decision herself and had looked for advice and wanted someone to tell her what she should do.

IB07 – ‘ I was unable to go to the evening thing (information evening), but I did speak in depth with one of the people there at the hospital....I was trying to ask the doctors and nurses and nobody would actually say yeah I think you should have this done or no you should have that done. It’s all my decision but...I just felt that I didn’t have enough information. ...but there again the more information I found the more that I felt ...at the end of the day again we are coming down to an individuality. ...And I haven’t got the medical knowledge to say well okay I need my ovaries or I don’t need my ovaries, that’s what I wanted someone to tell me’.

Influences

Participants were influenced in their expectations by people around them who had had previous experience of a hysterectomy. Participants were concerned that from what other people had said, that they would not be able to do much after surgery, and they were inclined to believe the advice they had been given in order to learn from them and avoid delays in recovery.

IB14- People told her things *'That I won't be able to do much at all. They have said that you will have to sit quiet and just toddle round the house a bit.....And I shall be happy to do what they say because I want to be right.'*

IB16 *'..my sister's had a hysterectomy, my mum...my auntie and I've listened to all their experience. My best friend as well and em they are all back at work. You know they are all back to their normal selves'.*

IB22 *'Information that I have shared with friends...you know nothing too negative but just that they have been quite fatigued and tired, off work for long periods of time, but overall they basically said you know that they made the best decision. But you know I know each individual is different so I am just kind of wondering what is going to happen in my situation'.*

IB21- sister had the same – expects recovery of 6 weeks *'rather than 12 weeks'.*

This participant was due for a VH but took advice from her mother who had had a TAH but she did not expect that her recovery was going to be any different due to the route so was inclined to listen to the advice.

IB09 *'Just what I won't be able to do really and how long I won't be able to do them for. But she has been really supportive and encouraging.'*

A participant who was expecting a LH talked about the advice she had received again from women who had had a TAH.

IB22 – *'you know they have been quite fatigued and tired, off work for long periods of time.'*

Again, she did not expect any difference due to fact that her surgery was planned for a different route.

One participant did talk about how she was surprised at the experiences of others and that she expected her recovery to be better.

IB06 *'They said at work get your friends to make you a sandwich before they leave you and I'm thinking I will be able to make a sandwich. Surely I will be able to make a sandwich. I don't think I will have my arms cut off.'*

Some participants were influenced by their previous experiences of other types of surgery they had and were worried about the hysterectomy being a larger procedure. In particular, they spoke about how they would cope with recovery in their different circumstances from their previous surgery.

IB005 *'Well, when I broke my leg, things like, you know when you are straining to do something or you are finding it a little bit hard and just in that sort of way. I think you know yourself.'*

IB010 – *'Em quite worried in one respect. I've had lots of surgery before....So there is a part of me that knows what's coming. Em but it's the, this is a little bit more serious than what I've had done before and it's the after effects I'm more concerned about. Having my children to cope with. And how long it's going to be before I'm back to normal so to speak. Like with my husband working away'.*

Previous major surgery – IB21 *'And as long as they give me injection for being sick after...I will be fine.'*

Part II Expectations Pre Surgery

Expectations about length of hospital stay

Participants all talked about confusion in their expectations of how long they would stay in hospital. They attributed this mainly down to conflicting information they had received from various health care professionals, including discrepancies between their consultants and the pre-operative nurses.

IB06 laparoscopic- *'He [consultant] said to me if you choose a hysterectomy you will be in hospital for one night, within a couple of weeks you should be feeling more or less back to normal, then when I saw him in July and I said is it just one night, and he was like maybe two or three, and then at the pre-op the nurse said usually 3 to 5 nights it might you know be longer...So now it's almost gone from sort of like 24 hours, which I could cope with, to sort of 3 nights minimum which is like oh my God, to maybe 5 may be longer'.*

Other participants in the laparoscopic group expected to stay in between 3 and 5 nights as well.

IB24 *'3-4 nights'*

IB22 – *'Hospital stay 3 to 4 days'*

IB21 – *'I am in Tuesday and hoping to come out Friday'.*

IB16 *'I suppose they said the average is 4 and I think ...I would be a bit worried if I was only staying for 2.'*

IB13 *'Em originally they said 2-4 days, now they are saying 3 -5... Because they were not aware of the problems with my bladder and the problems with my discs.'*

In the vaginal hysterectomy group, most participants expected a stay of 3 to 5 days.

IB09- Mum had TAH *'I mean mom had hers on Friday and came home on the Monday....I mean I have read the leaflets and the leaflets say 3-5 days'.*

One participant talked about how if she needed to stay longer than she expected, it would be in her best interests. She felt that if she was in hospital then at least she was in the safest place and that if they kept her in she probably needed the time in, but would like to come out as soon as possible.

IB005 *'Well obviously I'd rather be out than in hospital, than lets, so if I was ok on the Sunday I would rather come out. The sooner the better'.*

Expectations of recovery

Pain was something that participants associated as a marker of their recovery. They talked about how pain would concern them and stop them from doing things they might feel they could.

IB07 *'But if you get more pain....then obviously something's a bit wrong so you have to get advice'.*

There was no difference in the expectations of participants in the activities they would have to refrain from regardless of the route of surgery they were having.

IB005 (TAH) – *'I suppose I'm going to have to stop myself from you know just like bending down, picking things up and you know changing the cat litters, just things that I do every single day.'*

IB14 (VH) *'I can't go picking my grandson up.'*

IB14- *'I'm going to be staying upstairs for the first few weeks. I am going to stay out of the way.'*

IB24 *'There's an old saying that once God made your body perfect and then once the doctor get inside you, you are not normal again cos that cut will always be there....It's an old saying from my parents...You know if it's gonna heal properly you know'.*

IB010- *'I'm not looking forward to staying in.. Because I can never sleep.'*

IB01- *'I think you can heal better at home'.*

Driving 3 weeks from pre-op nurse

IB06 (LH)– Driving 3 weeks- at pre-op, patient thinks it will be 6 (from family member who had CS).

IB16 (LH) *'Well I am hoping maybe after 6 weeks I will feel well enough to think about going back to work.'*

Thoughts about recovery

All groups regardless of route of surgery had similar concerns about their recovery. This stemmed sometimes from the experience of other people they knew;

IB005 (TAH) – *‘three of my closest friends have had hysterectomies.....all of them have actually said the one thing that is the worst for all of them, is the terrible terrible constipation after. And that’s what they said they found the hardest. I mean some of them said they went home from hospital they would be there all night crying. Trying just to go to the toilet because they felt bloated and that inside’.*

Recovery expectations were associated more with the individual, there were participants who were keen for a fast recovery and those who felt that they would not want to rush themselves.

IB16 (TAH) *‘I am hoping that I can manage to do the general household stuff pretty quickly...Em, you know manage to go back to work. You know as soon as possible..Well I am hoping maybe after 6 weeks I will feel well enough to think about going back to work’.*

Some participants were quite negative about their immediate recovery and the effect it would have on their lives and responsibilities, again this trend was seen across all surgical routes;

IB07 (TAH) *'I live on the other side and he goes to school (son) and most of the people live by school. It's definitely a car drive away...So you have got to walk to the bus stop, wait for buses and I couldn't do that in the beginning anyway'.*

IB09 (VH) *'You won't be able to walk...I probably would't even get to the end of my road'.*

IB06 (LH) *'It's almost as if things will never be the same again but 6 weeks in reality is nothing'. It just seems, oh well I can walk 4 miles any day I like now. But I am not gonna be able to do that next week. And, you know, I am gonna struggle to get out of bed and I don't wanna be, you know gonna have to be dependent on people and have lots of people around me that I am not really looking forward to'.*

In this part of the study, most women spoke about physical and behavioural recovery rather than emotional or sexual. These areas were addressed with prompt questions later.

One week after surgery

In general, regardless of route of surgery, participants expected to not be able to lift heavy things, do the vacuuming, bend or stretch. A number of participants had expectations but were mindful again that there is individual variation and that their recovery may be different. They spoke about listening to their bodies.

TAH Group

IB18 – *‘I know I won’t be ironing’ ‘Em just think its down to your body really and you listen to your own body.’ ‘I won’t know until I you know probably experience pain or whatever...That I’m not supposed to be doing what I am supposed to be doing’.*

IB008- *‘Em one of the things I suppose I think I won’t be able to do is probably wear normal clothes for a while. Eh, I have got a few loose things that I have not thrown out’.*

IB01- *‘Just me normal things, like cleaning up and vacuuming and you know.’*

IB01- *‘Like I say it all depends on that person...you know and I think me myself, I am a stronger person. I am not gonna think I’ve had that operation like oh I can’t do this. I am still gonna get up and try.’*

In the LH group, there did not appear to be any difference in recovery expectations from the TAH group and were mostly around lifting, vacuuming and driving.

IB16 *'Maybe just walk up to the shops which is 10 minutes' walk from my house'.*

IB22 – *'I won't be able to push them (kids) in the chair (pushchair) or lift them out of the bath.'*

IB13 *'I know I've got to sleep and eat properly.'*

VH Group

In this group, there were some specific concerns around pain when sitting down, and opening their bowels. They expected more pain with both of these activities due to the positioning of their vaginal scar.

IB14 *'sitting down in the bath might be a bit awkward. And the toilet. Just going to the toilet because I remember when I had the children I was quite stitched up after I had the children. I am just hoping my bowels and all that, it's a terrible thing to talk about , but yeah I don't look forward to down there.'*

One month post-surgery

At one month, there was again little difference in the expectations of participants according to their route of surgery. In the TAH group, participants felt they could partake in light exercise only, lying down exercises, no driving, no sexual intercourse and no heavy lifting still such as children. Again, there was reference to listening to your own body and individual variation.

IB005 *'doing the normal things then...Just like going back out socialising and just doing the normal things, like putting the washing on and things like that. I won't be vacuuming or anything like that'.*

IB005 *'Just take it at my own pace and sort of, I think you can tell if you are over doing it with your own body'.*

IB10- *'Em-, well I won't be back at the gym.'*

IB18- No heavy lifting *'Will have to do light jobs like working on the wards' – works in theatres. 'They reckon I might be at work after 6 weeks'.*

One participant was optimistic and felt that they should be almost back to normal in the TAH group.

IB01- *'I should be hoping by then things would be getting back to normal then. I would be expecting to be getting, not 100% but at least 85% back to normal.'*

In the LH group, there were participants who felt that they may be driving by 1 month but on the whole, their expectations were similar to the TAH group. Again, they expected not to be able to do strenuous exercise, vacuuming and listening to their bodies.

IB21- *'I'm gonna see how I go and then perhaps in a month I might be driving.'*

IB06 *'I hope after a month I will be able to do almost everything...Maybe not vacuuming but maybe.'*

IB16 *'I don't think I'll be taking any strenuous exercise.'* *'Just general things around the house.'*

IB22 – *'No driving'*

IB13 *'Well hopefully I will be able to do the majority of things apart from like real physical exercise.'*

One participant talked about how she was not expecting to be back at work because of the advice her doctor had given her. None of the group talked about being back at work by 1 month.

IB06 – *‘The consultant said we sign you off for 6 weeks straight away’.*

There were similar expectations around sexual recovery regardless of route of surgery, and this seemed to be due to what they had been told;

IB22 (LAH) *‘I understand that I can’t be sexually active until maybe up to 6 weeks or so.’*

IB10 (TAH) *‘The sex possibly not as it says on the thing. ...on the leaflets that potentially it is 6 weeks.’*

IB09 (VH) Sexual *‘And like after childbirth as well, you have to refrain from sexual intercourse for 6 to 8 weeks anyway so it’s just the same to me’.*

The VH group had similar expectations at 1 month around driving, strenuous activity, heavy lifting.

IB09 *‘Possible drive, depending on whether you can get the seatbelt round you with my insurance’.* IB09 *Has a night out paid for* *‘Well. I have paid for it in the hope that I’ll go. Its gonna give me something to, to work for’.*

IB14 – *‘Would not be expecting to do vacuuming, going out shopping and driving, picking up grandson, gardening and dancing, driving – 6 weeks. ‘Yeh I’m worried about the muscles. I am not sure what happens about your muscles so I will have to ask about that.’*

Expectation of recovery two months post-surgery

At this time period, there were differences in the expectations of recovery in the different surgical route participants, but this was more marked in the VH group. The TAH and LH talked about how they should be expecting to get back to normal and start thinking about exercise again, vacuuming, pushing children’s prams, shopping and sexual intercourse. The VH group were expecting to be careful around lifting and strenuous housework still at this stage.

TAH group

IB07’ *As long as I can do a bit of Christmas shopping and make sure that, coz he (son) still believes in Santa so I’ve still gotta hide the presents so whether I out them in the attic this year I don’t know’.*

IB10- *‘I would hope 2 months after that the only limitations I would have would be at the gym. And I would expect that everything else would be back to normal.’*

IB01- *‘I’m hoping by the 6 weeks I will be flying round the block.’*

There was still reference to not pushing it and taking account of your body's signals.

IB18- *'More or less the same but not pushing it'*

LH Group

IB21 *'I should be as fit as a fiddle'.*

IB06 *'Expecting to do everything and will be completely back to normal'.*

IB16 *'Em hopefully I will be back to normal.'*

IB013 *'Intercourse obviously cos they reckon 6-8 weeks for that. ...obviously a lot of it is common sense isn't it. Your body tells you how you are feeling'.*

In the LH group, there were differences in expectations about whether they would be going back to work and these appeared to be related to their activity type at work.

IB16 – *'work 6 weeks'* (office worker).

IB22 *'Active but not necessarily back to normal. No vacuuming, thinking about going back to work (nurse).'*

VH group

IB09 *'Heavy lifting might hurt, can't do some house work 'But I hope to be able to at least walk to the school and pick my kids up.'*

IB14- *'No heavy shopping or picking up grandson. 'I may be able to take him to playschool'.*

Recovery expectations three months post-surgery

All groups felt that they would be back to normal by 3 months. The LH group were more optimistic and used more positive words such as ‘great’ and ‘distant memory’ and being back at work, whereas the TAH group were talking about starting to feel normal.

TAH group

IB10 – *‘thinks should be able to do everything’*.

IB18- *‘By 6 months I will be more or less doing everything’*.

IB005 *‘Actually in my own mind I think I will be off about 3 months (from work)’*.

LH group

IB21- *‘Oh I’ll be great’*.

IB06 – *‘Oh God, it’ll be a distant memory’*.

IB16 – *‘Can do everything’*.

IB22- *‘Hopes to be back at work then’*.

IB13 *'I should be fine.'*

Again, the VH group were more cautious in their recovery expectation at 3 months.

IB09 *'I would like to be doing everything....work is my only grey area....But that's something obviously my doctor and hospital would discuss with me.'*

IB14- *'I was hoping I would get to a bit of normal. Exercise, I will probably have to ask about that.'* *Didn't think she would be completely back to normal'.*

Expectations of sexual recovery

All groups regardless of their route of surgery felt that there would be a positive change in their sexual functioning. There was some apprehension about sexual feelings and how to approach the subject with their partners.

IB16 *'Well I'd like to be but at the moment, no, well it would be too painful...Well I am hoping that my body feels better afterwards, so you know I am not worried about it but I am hoping I am optimistic that maybe I will get back to being a normal human being that can take up any activities'.*

IB21- *'Oh (it will be) a lot better. Because we are not at the moment...We haven't for about 18 months. Because every time we get in the mood it just happens. You know...I bleed you know and I am in pain.'*

IB22 *'You've asked me about how I, how I feel you know, I am going to approach things sexually, but I was wondering, I mean some people probably have reduced feelings afterwards, and for some it makes no difference. But you know that's probably something I probably need to sit down with my husband and talk about. I am just wondering you know it, how it will affect me personally.'*

Thoughts about surgery

Positive

Positive cognition was framed around trust in doctors, going through the stress of surgery in order to gain a solution to their problems and even a better quality of life than they have had (pain for gain), focussing on a good outcome and the positive experiences of others. This was similar across all surgical routes.

TAH group

IB16 *'Well I know I trust the doctors here and I know they are gonna do their best. They've got the best available medication...so I know I'm gonna be in the best hands really...you know that I'm gonna be on the mend'.*

IB22 *'Well I'm quite nervous to be honest. Just in case something should go wrong but I have gotten to the point where I am quite happy that I have made the decision, you know between my gynaecologist and myself. You know based on the problems that I have been having in the past'.*

IB01 *'I'm just thinking to myself now hopefully all the problems will go away...You know the periods, the heavy periods, the pain, just hoping it all, I hope it's worthwhile actually.'*

VH Group

IB01- *'Everybody's told me who I know who's had an hysterectomy, it's the best thing they ever did, even the woman at the bus stop said to me today, she was telling me it was the best thing that ever happened to her.'*

IB14 – Hoping to get back to dancing *'I found that awkward , planning holidays'.*

LH group

IB006 – *'So once that's gone (bleeding) you know, I will be able to go if people are saying oh do you wanna walk up mount Everest at the weekend I will be oh yeah course...I haven't gotta worry where the toilets are.'*

IB21 *'Em, quite looking forward to it actually. It's gonna change my life hopefully'.*

The LH group talked about how they were still comfortable about their decision despite the risks associated with surgery;

IB21- Positive despite risks- *'it can perforate your bowel or whatever but I am kind of not bothered about that. You know I mean I just need this hysterectomy.'*

IB22 – *‘Well I’m quite nervous to be honest. Just in case something should go wrong but I have gotten to the point where I am quite happy that I have made the decision, you know between my gynaecologist and myself.’*

Negative thoughts

Participants who talked about negative cognition were those who had a poor experience previously of surgery, mostly associated with anaesthetic or complications;

IB16 (TAH) *‘It’s just that I have had a few operations in the past and I know what it’s like when you come round and you don’t feel too good and you know the amount of time that it does take to recover sometimes.’*

IB14 (VH) Anaesthetic, pain after. *‘Because when you are put out....I mean you don’t know whether you talk in your sleep or something or what. So I am a bit apprehensive because people say that you feel sick.’*

IB13 (TAH) *‘My last operation they burst the discs in my back and damaged my bladder....so obviously there are some of my concerns...Being catheterised after the operation. They said it could be anything up to 72 hours. I am worried about that cos my bladder doesn’t, I don’t know when my bladder is full. The operation itself doesn’t worry me. Em, apart from when my sister had a laparoscopy, she nearly died.....she got septicaemia in it....I have friends who have been in. Like women who have had*

hysterectomies and you know, so I've seen that not all of them go the same, so what will be will be'.

There were also participants who were afraid because they had not experienced surgery or a hospital stay before;

IB06 (LH) *'Petrified, I've never been in hospital before. ..I'm scared that I'm gonna wake up in pain. ...and the whole hospital situation is very much out of my comfort zone....and because I've lived on my own for a while, I am used to doing everything for myself'.*

IB21(LH) *'I am dreading it..Being in hospital. The thought of just being in hospital terrifies me...But the MRSA things like that you know.....but the operation no. Not at all, I'll be in and I'll be out'.*

There were anxieties around being able to carry out their usual roles and responsibilities such as child care and housework, as well as lose their independence and rely on others;

IB07 (TAH) (single mother) *' I am anxious, em not just because of the surgery but because my son has got to go and stay somewhere for a week and I'm not gonna see him....coz I've no family in the vicinity....so it's just extra extra pressure I suppose. ...He is off school that week it fell really well actually, so he will be in Manchester with my brother'.*

IB010 (LH) Leaving children- *'And the fact that they are gonna go and stay with my parents on Thursday and I've got to say goodbye to them and I get emotional and that and I've never really felt like that.'*

IB24 (TAH) *'My independence is gonna go..In like cos I won't, for a while I won't be able to tidy up, I won't be able to cook, I won't be you know to do like, somebody is gonna have to take over everything and it bothers me'.*

IB01(LH)– *'I just thought I'm gonna be bed ridden and that's what I didn't wanna do that'. I spoke to the nurse...she says that I would be able to walk to the little corner shop'.*

IB06 (LH) *'Scared to death...I'm scared that I'm gonna wake up in pain...That I'm not gonna be able to cope very well with the pain and with the whole hospital situation is very much out of my comfort zone. Coz it's completely unknown.'*

Only one participant talked about the fear of sexual recovery and what it will be like afterwards;

IB01 (LH) *'I'm worried about all the dos and don'ts you can do. But my main issue was em sex. That was my main worry and but obviously I spoke to somebody (the pre -op*

nurse) about that....and I was quite happy with what they told me about it. You know. That it's just as normal as it could be.'

Again, there were similar negative thoughts about surgery and surgical recovery across all surgical route groups.

Loss of fertility

There were a few women who talked about the effect of surgery on their fertility and how this had made them feel;

IB13 I'll cry my eyes out, but you know, like I say I don't want no more children so that's not gonna be, it's not like as if em Iv'e been just told I've gotta have this and no choice in the matter'.

IB24 'My partner hasn't got any kids...I feel really emotional that I have a kid and he hasn't got any. But I have to do it. So I am just thinking down the line. Where we go from here, cos he is gonna want kids. But he doesn't want any you know. I don't know how he is gonna react. He said he is fine..but you never know later on'.

IB07 (LH) 'I'm too old now to have any more children...But..I don't know really. It's..It seems a bit sad the thought of it'.

Some women were philosophical or had decided that they did not want children and so did not mind losing their uterus.

IB06 (LH) *'I've not had children so I've not had any sort of major interference with my body. You know I've not had any other illnesses. So I suppose when you have a child you know a bit about what maybe is to come. I mean I know most women in my situation would be like oh gosh I can't have any children...And here I am saying I'm afraid of the pain. It's like oh well if I had wanted a baby I would have had one years ago or whatever...I just want an end to this bleeding'.*

Part III Post-surgery experiences

1. Post-surgery attitude of others

Some women spoke about the attitudes of family members and the effect of surgery and hospital stay on them.

IB17- *'Told the kids that I was gonna be going into hospital for a couple of days but I would be back which scared my son a little bit. Cos he is sort of 7, so he was a bit concerned about me going in but I promised him that I would be fine, that I would be back, you can come and see me I won't be long'.*

This participant had been quite tearful before surgery about whether her husband would understand and how he would react to her recovery needs after surgery. She went on to talk about her experience of how this was after surgery:

IB02 – *'He was leaving me half a kettle of water, so I could just tip it and make me own cups of tea...I says I'll get by. He'd do me a sandwich you know, ready for me tea, make sure I was fed before he went to work.'*

Effects of surgery and illness

Participants who talked about the effects of surgery were positive and spoke about how it had solved their problems and improved their quality of life;

IB05 (TAH) *'I feel like I know what it's like to be in your 80s or something, to be a really old person, and it's sort of been reversed and I am just really happy.'*

IB17 (TAH) *'I had to sort of limit what I could do cos of how bad my periods were. Now I can do whatever I want it's gonna make no difference whatsoever.'*

IB21 (LH) *'Quality of life much better now, can do much more 'Gardening, going out, I used to have to take a bag with me with pads and a new set of trousers or skirt. I am looking forward to my holiday...last year was horrendous. I had a period from the time I went to the time I came home. You know and it was just, I couldn't do nothing. I felt dirty and you know even though I was showering every day, well about 3 times a day, it was just horrendous. But this time I am looking forward to it.'*

IB06 (LH) *'I've got 3 little dashes on me belly. They're nothink. You know, they're nothink and to have you know such a major thing removed.'*

IB 13 (LH) *'I had gone from this tired, bleeding person to like this happy sparkly person. So like totally changed me straight away.'*

Experiences of hospital and surgery

Here there were differences between the three surgical routes, in particular a lower length of stay in the LH group.

IB05 (TAH) *'I had it done on Tuesday late afternoon, Thursday morning they let me go home. . So I just went back and had the stitches out 5 days later and then just been getting better and better. 'I was thinking I would be in for about 5 days'. 'It was right to go (home when she did), and I knew then I could have gone straight back in if there was any problems'.*

IB17 (TAH) 2 days *'I thought I was gonna be in there until Monday (extra 4 days) to be honest'.*

IB8 (TAH) *'I was in on Wednesday and came out Friday.. I was very pleased to come out...it was exactly right for me'.*

IB21 (LH) *'Tuesday to Friday, 1 day longer than expected because she had a cold'.*

IB06 (LH) *'You know I wasn't in hospital long. I was only in one night...And I was out, which I was delighted about cos I was really scarred about my hospital stay.'*

IB06 (LH) *'I bought two nighties for my hospital experience and I should have left the tags on and taken them back.'*

One participant in the LH group (IB22) had a prolonged stay which was not associated with any complications of 3 days, which was similar to the TAH group.

Actual recovery experience

The actual recovery experience and mile stones were more associated with the individual, their circumstances and complications rather than the surgical route.

TAH Group

IB05 *'after 3 weeks it was like a bit of bleeding again and I thought oh no, you feel like your insides are falling out...but I just went to the GP and got some antibiotics. Cleared up then and just so relieved and so happy to have it done.'*

IB05 – *'It's slow because you feel really good and then you probably overdo it a bit, I don't know just walking round, it's like the weight kind of collects just at your stomach and you get this numb, your stomach goes numb. At first you feel as if it's some kind of a space hopper or something you know, sort of you know from the inside. But that just gets less and less.'*

IB08- *'I was out and about 2 days afterwards...I started my exercise regime ...on Saturday which was the day after I came out of hospital I walked round the garden. And on Sunday I did 10 minutes' walk.'*

IBO8- Mother was ill and had to go on the train to Gloucester herself around 2.5 weeks –
‘I did feel extremely tired afterwards and my stomach felt, did feel swollen and bloated’.
She didn’t feel she was doing herself any harm – ‘I just thought, I would get warnings if I
was doing myself some harm and I didn’t feel that. I just felt very tired from that.’
IBO8- At 8 weeks doing everything – *‘I think I hovered after about 6 weeks.’*

IB05 – *‘So now there is very little I couldn’t do’.* (3 months).

VH Group

IB03 *‘Very tired the first couple of weeks...Extremely, I was sleeping 16 hours a day.*
Don’t know if that’s normal or not.Em, had a bit of an infection. Three no two lots of
antibiotics’.

IB03 *‘And I just remember my throat was so sore, so dry, but obviously from that*
breathing pipe.’ ‘I didn’t like the catheter’.

IB02 *‘In fact my biggest problem was remembering that I’ve had something done and I*
mustn’t lift heavy weights.’ ‘But once I had the drip off and the oxygen off and all those
tubes out and I just trotted off to the bathroom as I wanted, I was fine.’

IB03 Pain – *‘Fine, I didn’t even take paracetamol. I did as a matter of routine the first*
couple of days, but after that.’

LH Group

IB22 *'It's been really good'.*

IB22 *'After the first week or so, I wasn't in a lot of pain and I kept taking my painkillers, so I didn't have much problem at all, and I was able to go up and down the stairs.'*

IB22- *'I went back to work after what 10 weeks'.*

IB06 *'And I never felt ill in myself. I was tender and uncomfortable at times but it wasn't really anything to complain about. You know I've felt worse when I've had the flu.'*

IB06 *'Well I didn't really lift anything for weeks and when I first vacuumed after about 6 weeks cos I had to, em it took my breath away.'*

IB06 – pushed herself with walking a bit further every day but then felt tender *'And then I'd just lie down. I mean it soon got better and then I was angry with myself thinking you have had major surgery.'*

Most participants did not drive until after 6 weeks, regardless of surgical route, however, there were two participants who drove much sooner. One had a TAH and the other had a LH.

IB02 (TAH) - Driving for 3 weeks (interview at 8 weeks) seat belt annoying – *'Because I am wearing it round the bottom half, it gets quite tight when you are driving.'*

IB06 (LH) Driving after 3 weeks. Work after 8 weeks GP said '6 weeks is optimistic.'

Experiences versus expectations

Most participants talked about a better experience of recovery as compared to their expectations in all groups. This was not particularly associated with route of surgery.

TAH group

IB8- *'My expectations are usually quite realistic I think.. Erm, I suppose it's from the information I've gathered and em probably past history of surgery'.*

IB05 *'Like just walking, for a long time....and I knew I felt that I could really do some damage if I kept that up. And so I feel as I needed to lie down cos that pulling and that, that's gone on for a long time really; which was to be expected. But I just wasn't expecting it'.*

Influences from other's experiences were negative

(IB05) one woman had a hysterectomy around her 40th birthday and was depressed for 10 years and I thought *'oh I'm gonna feel really miserable and, but I didn't I was just so relieved that I had it done and so happy'.*

The same lady was prepared to have no sex life and was pleasantly surprised

'Perfectly alright. That was my main worry', be depressed and have a 'horrible scar like a ladder going up your stomach. And the scar you can't even see any stitches or anything, it's just brilliant'.

IB08- *'Emotionally 'no different to usual'*

IB17 *'Recovery was a bit faster than what I expected. I was up and about within sort of 2 weeks. I was pretty much back to normal within 4 weeks as opposed to 6 which they said. I did have an infection. But I got over that quite quickly.'*

This participant (IB17) said she had a positive attitude; *'Once I have decided something I go for it with no ends or buts about it I will do it.'*

VH group

IB03 – *'They were saying well you can't even lift a kettle and things. Well I did....Day one.'* How was she *'Fine'*.*'Em after about 2 weeks I mean I went shopping.'*

Vacuuming after 2 weeks. IB03 6 weeks off work – right for her.

IB02 – *'Much better than I expected'. 'Because someone told me that if you have an anaesthetic it sometimes knocks off a few brain cells and I haven't got many to be knocked off. I can't afford to lose any and I thought perhaps I am a bit worse. But I don't think I am now.'*

IB02 – Felt she could have gone home earlier (stayed 3 days) but it would have been *'unwise toSilly to rush things'*.

LH group

IB22 *'What I was worrying about before, I don't know, it's all gone. I think I was just unnecessary worries really'*.

IB21 *'It was plain sailing actually. I have heard that many rumours that you know they cut through to your bowel..... it can happen can't it, you get to sign a consent form saying that if any of these symptoms happen you know it does happen. But I have had nothing and I am so grateful for that, you know cos it was a big concern when they go in blind that they can perforate something.'*

IB13- Driving after 3.5 weeks *'Better than what I thought. I was doing things more of less straight away. I didn't really feel like I had had a major operation.'*

IB13- *'I had more pains with my previous problems than what I did with the hysterectomy.'* At 3.5 weeks was completely back to normal'.

Some participants talked about being well prepared and how this has made their recovery better;

IB22 (LH) *'Well I think that was why everything went smoothly, because I had you know good preparation before and I had leaflet that I could go back and read information that*

I couldn't remember, you know, so I was well prepared, you know mentally and otherwise. 'Thinks the method used improved her recovery.

Participants talked about listening to their own bodies in all the surgical route groups;

IB17 (TAH) *'I have faith in sort of my body will let me know if I am pushing myself too hard. And then I would have stopped. But cos of how well I could, I just got on with it.'*

IB03 (VH) Expectations – surprised because *'I thought I would literally be bed bound as such.'* Influenced by what people told her, *'But the one thing I did do and it always stuck in my mind. Listen to your body'*.

Some participants in all surgical routes had a worse recovery experience than they had anticipated;

TAH group

IB05 – Was worried about sex life mainly – *'perfectly alright. That was my main worry'*.

IB02- *'I was expecting to be back at work within the 12 weeks.'* Struggled with washing hair over a bath, described her recovery as a 'rollercoaster'. Uncomfortable going up and down stairs. Post-operative wound infection during first week – *'I couldn't even put me drawers on. Everything was catching. It was really uncomfortable...it was all like pulling.'* But compared it to her emergency CS 27 years ago and *'It brought it all back'*. Remembers her sister helping her wash her hair over the bath then as well.

IB02- *'it took me a long time to actually start sleeping on my side...Em, about 12 weeks.'*

IB02 Did not anticipate that she would need different clothing due to pain and tenderness *'I've managed to find some very elasticated underwear...They come up to my belly button and there's no seams.'*

VH group

IB03 *'The only thing I was surprised but I had been warned, the amount of wind that you get....and the bloated feeling, it's horrible. I mean that it was really uncomfortable, I would say it was more uncomfortable than the operation'*.

IB03 *'So, it did get me down for a while, you know, you think oh I am not a woman, not a proper woman anymore, I can't have babies.'* *'It's not like having breasts removed. Because it's not physical but mentally it did affect me for a bit. Just a couple of weeks but no I feel really good.'*

IB03 – Kept ovaries and was surprised to get PMT *'I just thought well I won't have periods I won't get PMT.'*

IB03 – had an infected haematoma *‘And then when I had the bleed..Em...they said they may need to open me up if the bleeding didn’t stop...Which scared me again. Because I wasn’t mentally prepared to be opened up.’*

IB06 – Wind pain was worse than expected and used a full tin of chocolates to put her feet on when she was on the toilet to ease the pain. *‘I wish I’d done a swap phone numbers with one of the ladies who went in on the same day to see how they were recovering.’*

Effect of healthcare professionals

Regardless of surgical route, there was a strong influence of healthcare professionals in the recovery experience.

IB05 (TAH) *‘I felt like he had really listened to me and done what I wanted (surgeon)..... ‘I mean they are there, there’s a team there and you know they were just brilliant, you felt safe.’*

IB02 (TAH) *‘Em, went for my 6 week check up with my doctor, just gave me a doctor’s note and sent me on my way...She wasn’t eh, she didn’t examine me or nothing.’*

IB06 (LH) Felt ward staff were very busy and so did not call them post operation when she had a question about her bleeding. *‘the nurses didn’t seem to be particularly expert, but you know there was the sister and everyone else seemed to be a student nurse.’*

VH group

OB14- *'But I am seeing a very good consultant, Mr X, he seems very reassuring'.*

IB14- *'I have listened to what the consultant said and what was said in the hospital and tried to just focus on that really rather than on other people's stories because you have to be careful of that.'*

IB14- *'And if I am told by the doctors don't do that I won't. Because I want to, I would rather get better.'*

IB03 *'The anaesthetist was lovely. Because I was more afraid of not waking....But em, he reassured me.'*

IB03 – Did not meet the consultant surgeon until the operating day *'Em I mean he was nice enough, casual laid back sort of thing. Which is great because to me if they are too formal you get a bit of a barrier don't you, you are afraid to ask questions.'*

IB03 – *'A night doctor. And he was really reassuring em and explained to me what had happened and you have had a rough day and I went yeah. He was lovely.'*

IB03 – When complication happened consultant *'To me the way he explained it in plain English and I knew what he meant...You know not like in the medical terms.'*

IB02 *'I tried to be sensible. And I think I must have succeeded because Mr X was very pleased with me.'*

IB02 – *‘Well you know my GP...said it is a nice little hospital you know, they will look after you well and you will be alright there, that encouraged me.’*

What to tell others

Again, there were no particular themes linked to the surgical route and what participants would tell other women who are having a hysterectomy, the advice seemed to be more related to the individual, their experience and circumstances. Advice included practical advice and ways to prepare themselves.

TAH group

IB17 *'be prepared for the swollen tummy and to make sure they get some clothes that would fit.'*

IB02 *'There's, there's a lot to it, I mean if a woman is suffering you've got the choices.'*
'I don't think you can prepare anybody mentally for it.' Talked about how she felt it would be easier to recover if you were slimmer, she felt the stitches pulled on her skin due to her being 'big'.

VH group

IB03 *'Just listen to what you are being, you know listen to them, they know what they are talking about basically, they are professionals.'*

IB02 – *'Bring sanitary towels and a good supply of clean pants'.*

LH group

IB21 *'Get everything sorted at home.....so all you've gotta do is when you go into hospital is think about yourself and think how you are gonna recover after.'*

IB13 *'I think mentally you've got to be prepared yourself. I knew that getting rid of everything would solve half my problems. Well it solved them all....I think it's down to the individual.'*

Discussion

Our study shows that there are very little differences between the recovery expectations and experiences of women who have a hysterectomy regardless of the route of surgery. The laparoscopic hysterectomy group showed a faster recovery period than the abdominal hysterectomy group and the vaginal hysterectomy group had specific concerns around their recovery which were associated mostly with a fear of causing damage to the stitches by heavy lifting. There are published data around differences in analgesia use and hospital stay for laparoscopic versus vaginal hysterectomy (110), our study did not compare analgesia use, however, our data did not show a clear reduction in hospital stay for the laparoscopic group.

Otherwise, they all had similar fears around the surgery, hospital stay, concerns about their responsibilities, attitudes around femininity and loss of fertility and sexual function.

I was surprised at the depth and complexity of some of the comments, there were emotive and powerful words used such as *'horrendous'* *'dirty'*, *'grabbed my life'*, I had not considered previously to enough extent that heavy menstrual bleeding would have such an impact. There was significant confusion around recovery expectations and difficulty in talking about sexual feelings. It made me consider whether as a society we have done enough yet to reduce the taboo around talking about sexuality and sexual emotions. As gynaecologists and health care providers, I feel this is somewhere we could improve on as well. Although this study did not aim to look at it, the role of women in this stage of their lives was highlighted. Women have so many responsibilities which include looking after children, wider family members as well as working for a living. The time that most

women have a hysterectomy for heavy menstrual bleeding is at their prime, when these responsibilities are paramount. It was evident that a number of women had struggled with prioritising their other responsibilities over their own health and put off treatment. Considering how common heavy menstrual bleeding and hysterectomy at this age is, I do not think that as a society we really appreciate the wider impact these medical problems have on society; nor do I think after this study, we do enough to support such women in my opinion.

I had not planned to compare how women felt after they had their ovaries removed versus conservation of ovaries, hence this data was not collected and the groups were not balanced in terms of those who had or did not have ovaries removed. The interviews did note some differences particularly in the expectations and feelings of emotion during recovery. In addition, I had not included any details or questions around whether or not women were on hormone replacement during recovery, which again could have affected emotional and physical recovery. These were limitations of the study; although a number of women did talk about having their ovaries removed and considering hormonal treatment.

Previous studies have reported that patients see the main advantage of a hysterectomy being no bleeding, with some women experiencing no pain or bloating after surgery. However only 13% reporting feeling strong, healthy and fit and even less (4.8%) reporting no social handicaps in terms of their life, job and socially and 16% reported negative attitudes towards hysterectomy including a feeling of loss and diminished

femininity (111, 112). There may be some cultural differences between the attitudes women have towards hysterectomy, which we did not explore as part of this study. In a Taiwanese qualitative study, women felt that once they had completed their families, the uterus was 'useless', with five themes: release from stress, inescapable fate, positive support, hoping for peace of mind and sense of trust as reasons for choosing the hysterectomy (113). Whereas, in other cultures, there was evidence of a more critical approach with consideration of the pros and cons of hysterectomy and the transition that occurs in self (114).

Sexual function after a hysterectomy is reported to improve or remain unchanged by many women (115-118), but a minority of women report a worse sexual function (118) . Our study found a positive effect in sexual function regardless of route of surgery, which concurs with the published literature (119), again we did not take into consideration whether ovaries were removed or hormone replacement was taken.

It is unclear from the published literature how much women value sexual function after a hysterectomy over physical symptoms such as pain and bleeding and it may be that health care professionals are still reluctant to give advice freely as part of a routine consultation and informed consent procedure about sexual function. Better pre-operative information about what to expect regarding sexual function after a hysterectomy has been shown to influence satisfaction with hysterectomy (120). Using the Female Sexual Function Index and a positive and negative checklist of sexual outcomes, this study showed that pre-operative education about potential negative sexual outcomes was associated with higher

positive scores with hysterectomy experience. For the women who received this information or asked questions about it in our study, we found there was a more positive experience after the surgery. Some women did not speak about the sensitive issue of sexual expectations or felt uncomfortable when they were mentioned. It is known that there is an effect of the interviewer on whether such topics are disclosed (121). The fact that the interviewer here was a female and gynaecology doctor may have had an effect on the responses from the women and need to be considered throughout this part of the study, both in a positive and negative way. The interviewer may have felt more comfortable discussing the sensitive issue of sexual expectations and experiences, but this may have been uncomfortable for some women, whereas other women may have found it easier to open up to a gynaecologist. The effect of the interviewer may have been even deeper with women perhaps wanting to 'say the right thing' to a doctor. We have tried to reduce this risk by structuring the interview with a statement around the personal beliefs and experiences of each women, and that there are no 'correct' answers.

Pre-operative education on other hysterectomy outcomes has been shown to promote self-care behaviours, encourages post-operative ambulation and reduces post-operative anxiety and pain (122).

It is likely that more targeted information which women find useful will help in the fears, expectations and recovery from all types of hysterectomy. In our study, there were both positive and negative effects of the wide variety of information available, particularly from the internet which is not managed or signposted. Specific aids such as websites, apps or videos, which are centred around women, and can be trusted by women should be

developed. Furthermore, we know that there is an association with pre-operative psychological wellbeing and positive recovery (123), which is affected by various techniques including information and empowerment. Negative recovery in this study was associated with a poorer pre-surgical psychological wellbeing state and minor complications post-operatively.

Confounding the issue of psychological recovery is confusion and conflicting advice around the recovery timescales and hospital stay with each route of surgery. We know that there is variation between the beliefs of health care professionals around recovery and this may explain the inconsistent messages women receive. A study of healthcare professionals and patients in the Netherlands has offered a prediction model of prolonged recovery at 6 weeks which may help with counselling women about their expectations (124).

Conclusion

It does not appear that the route of surgery had very much effect on the expectations nor the actual recovery experience of these patients. The only theme that was related to the surgical route was a lower length of stay in hospital in the LH group. Women's experiences were influenced by the information they receive, their individual perceptions about the surgery and recovery, the advice from health care professionals.

Chapter 5: Validated health status questionnaires to women who have had a hysterectomy

Aim

To study the quality of life before surgery, at 1 and 4 weeks after hysterectomy and at 3 months after hysterectomy in the qualitative group of participants.

Methodology

Three measures of quality of life questionnaires were given to all the participants in the qualitative study from chapter 4 at the four time points. These questionnaires were suggested by my supervisors early on in the study period. The various questionnaires were chosen to ensure that there was representation of health status, quality of life and disease specific measures for menorrhagia. The participants were asked to complete the questionnaires in their own time and post back to the researcher in a self-addressed envelope.

Measures

SF12 Questionnaire (appendix 14)

The short form (SF)-12 questionnaire was developed from the longer, well established SF-36 questionnaire as a shorter, more feasible version to assess health related quality of life (HRQoL). The SF-36 is one of the most widely used questionnaires for this purpose and it has been validated against other questionnaires such as the Nottingham Health Profile and the sickness impact profile for patients with coronary heart disease (125). The SF-36 was lengthy with 36 items and took a considerable amount of time to complete. The SF12 was developed by Ware et al reducing

the item number to 12, which was subsequently shown to require about one third of the time of the SF-36 to complete (126). The SF-12 correlated with summary measures for the SF-36 in a US general population observational study of chronic conditions and HR-QoL was shown to correlate with the SF-36 in a study of patients with coronary heart disease with no difference in standardized response means ($p < 0.001$) and the study concluded that the SF-12 was an efficient alternative to the longer SF-36 (127). The scores are positively correlated with health related quality of life.

EuroQol 5D (appendix 15)

The EuroQol 5D (EQ-5D) (euroqol.org) is a standardised measure of health status which is non-disease specific and can be applied to a range of health conditions and treatments. It consists of a descriptive profile covering mobility, self-care, usual activities, pain and discomfort and anxiety or depression, with a single index value for health status on the day of completion using a visual analogue scale which is positively correlated with health status. The EQ-5D is designed to be completed by the respondent for postal survey; it is designed in a way which is cognitively undemanding and takes a few minutes to complete. The instructions to the respondent are contained within the questionnaire. The EQ5 was developed and validated in 1990 by the EuroQol group (128).

Menorrhagia Outcomes Questionnaire (Short Form) (Appendix 17)

The Lamping Menorrhagia Outcomes Questionnaire is a disease specific questionnaire for heavy menstrual bleeding. It was developed to evaluate outcomes of hysterectomy and other procedures for treating menorrhagia. The questionnaire is validated (129) and

arose from a longer research questionnaire used in the North West Thames Hysterectomy Study(130). It was designed to evaluate clinical, quality of life and patient satisfaction outcomes 3 months after the procedure by a postal survey.

This questionnaire has 26 items to evaluate patient symptoms (2 items), post-surgical complications (3 items), quality of life (7 items) and patient satisfaction (5 items). As well as these disease specific questions, it collects data on demographics and 1 item on the patients' global evaluation of their bleeding and or pain in the 4 weeks before surgery.

The 17 items related to patient outcomes are scored to create two summary scales:

The Total Outcome scale (17 items) is an estimation of the patient's overall outcome, including clinical and quality of life and satisfaction.

The Quality of Life/Satisfaction scale (12 items) includes items on fatigue, irritability, depression, general health, improvement in symptoms, limitations in daily activities, sexual functioning, body image, speed of recovery, satisfaction with information about the operation and with the results of surgery, and willingness to recommend the operation to a friend with a similar problem. Scores are positively correlated.

The demographic and treatment related questions along with the global evaluation of symptoms before surgery are descriptive and therefore not scored to form summary scores.

Analysis of variance (ANOVA) was chosen as the statistical test to compare means of more than 2 groups. In our case, we had 3 groups and multiple time points. The ANOVA gives an F value as its comparison of means and significance of means is tested using a P value, where significance is $P > 0.05$. All statistical analysis was undertaken on IBM SPSS v-16 © by MS.

Health status questionnaire results

EQ5

EQ5 scores increased 1 week after surgery and then fell with time during the recovery period, being lower at 3 months than pre-surgery (table 5.2). Quality of life on the visual analogue score was lowest (low score is lower quality of life) 1 week after surgery, and again improved with recovery with a high score. The mean visual analogue scale (VAS) score was higher 3 months after surgery as compared to pre surgery; however this was not significant (table 5.3). Table 5.2 number of women who reported problems in EQ5 domains at each time point.

Results

Table 5.1 shows the number of women in each route of hysterectomy group. This sample was the same as the cohort who participated in the interviews in chapter 4.

Table 5.1 Participants

Route of hysterectomy	Number of participants
Abdominal	7
Vaginal	4
Laparoscopic	9

Table 5.2

Time	% (number) of women with problem					
period	Mobility	Self-care	Usual activity	Pain/discomfort	Anxiety/depression	Missing
Pre-surgery	17% (5)	10% (3)	34% (10)	31% (9)	24% (7)	0
1 week	28% (8)	14% (4)	52% (15)	52% (15)	17% (5)	41% (12)
4 weeks	7% (2)	7% (2)	24% (7)	24% (7)	10% (3)	52% (15)
12 weeks	7% (2)	3% (1)	3% (1)	10% (3)	3% (1)	59% (17)

Table 5.3 mean EQ5 scores at each time point.

Time point	Pre surgery	1 week	4 weeks	12 weeks
Mean EQ VAS	71.37	47.67	81.15	84.81
(SD)	(25.07)	(28.01)	(22.28)	(19.60)

Table 5. Analysis of variance (Anova) for mean EQ5 VAS scores according to route of hysterectomy and time point

	F Value	Sig
Pre-surgery	0.848	0.446
1 week	0.846	0.447
4 weeks	0.133	0.876
12 weeks	0.164	0.850

SF12 Results (Fig 5.1-5.48)

The SF12 results are presented to compare responses to each question by the routes of hysterectomy at the different time points.

SF12 was analysed by route of hysterectomy at the various time points. Due to the small numbers of participants in each group, statistical analysis was not done. There was missing data for all time points but the proportion of missing data increased with later time points after surgery.

In the pre surgery questionnaire, there were very little differences in SF12 responses for the LH and TAH groups. In SF12 question 4, less patients in the VH group reported that they were limited in their accomplishments as a result of your physical health in the last 4 weeks and no women in the VH group reported that they had accomplished less as a result of their emotional problems in question 7. The VH group reported less interference with work due to pain in question 8. The VH group reported feeling calm and peaceful more of the time as well as having energy more of the time in questions 9 and 10, and were the only group who reported no effect on their social functioning as a result of their health or emotional problems.

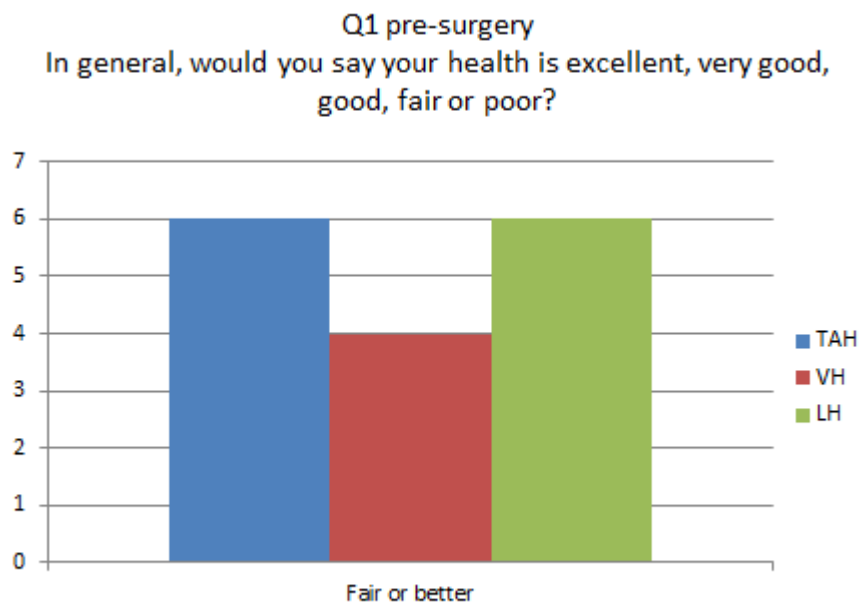
At 1 week after surgery, there was a reduction in quality of life as a result of physical health in all groups. Again, the VH group reported fewer limitations as a result of their emotional health than the TAH or LH groups (questions 6, 7 and 9), although 3 of the 4 women in the VH group did report feeling down in the past few weeks in question 11. The VH group also reported less interference in activities as a result of pain in question 8. At 2 months after surgery, the TAH group reported more negative answers in all domains, including questions 2, 3, 4 and 5 in the physical domain and its effect on activity, as well

as in the emotional domain for questions 6 and 7. The TAH group had a greater negative effect on role in questions 8, 11 and 12, and less vitality in question 10.

At 3 months after surgery, apart from question 2, the only group who reported any negative answers to any of the domains were the TAH group, although the number of women who had negative effects on quality of life was small.

General health subdomain

Figure 5.1



Physical Functioning Subdomain

Figure 5.2

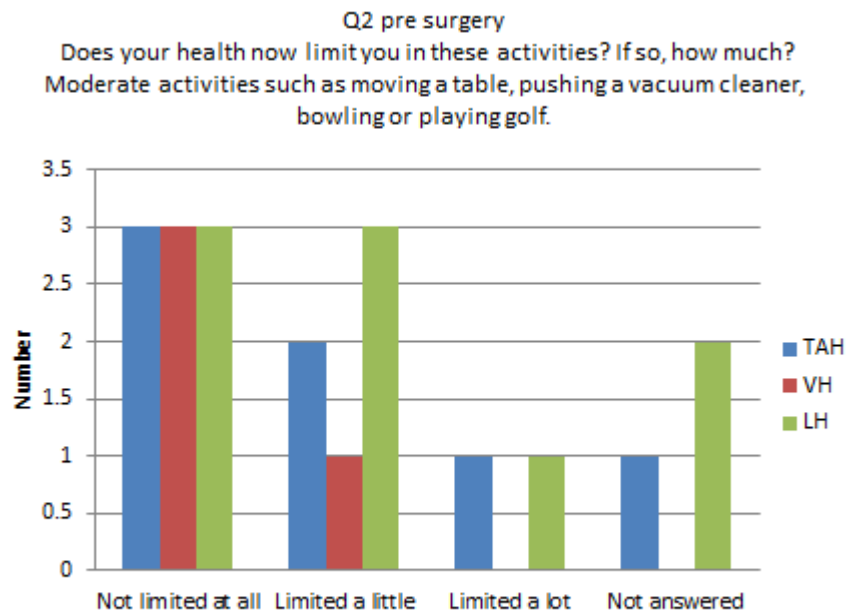
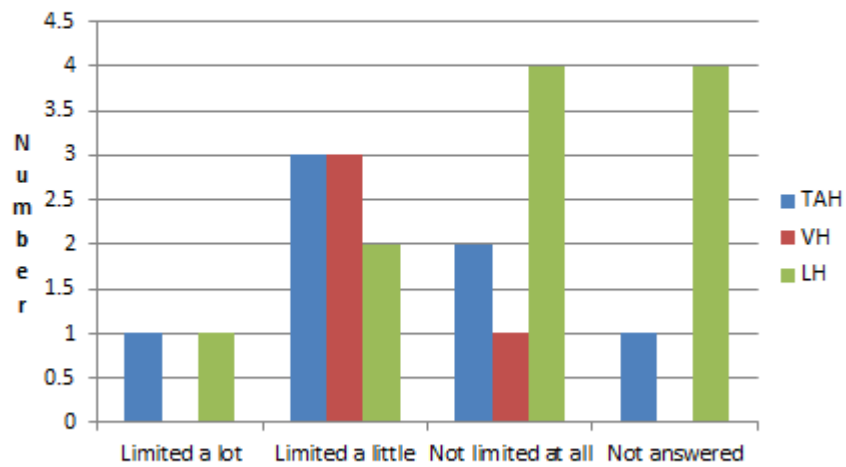


Figure 5.3

Q3 pre-surgery
Climbing several flights of stairs. Does your health now limit you
a lot, limit you a little, or not limit you at all?



Role Functioning (Physical) Subdomain

Figure 5.4

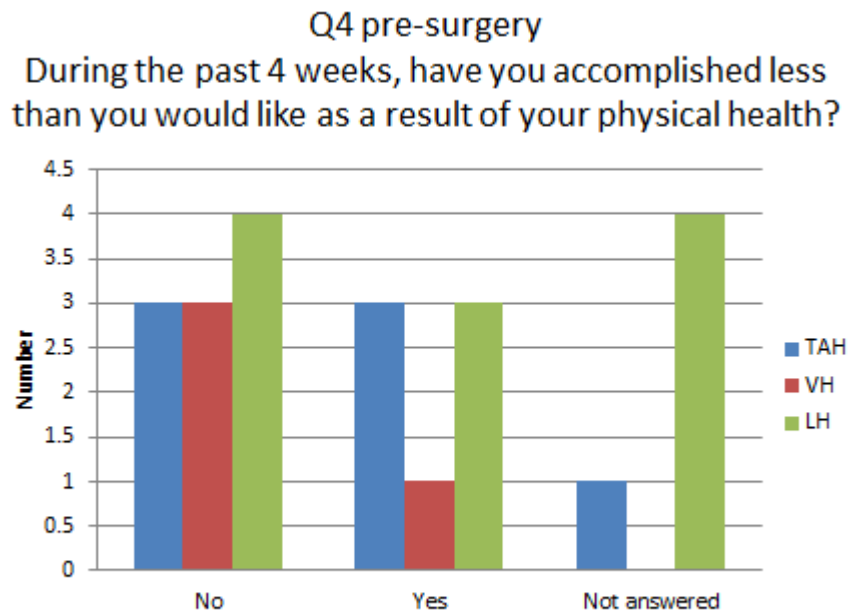
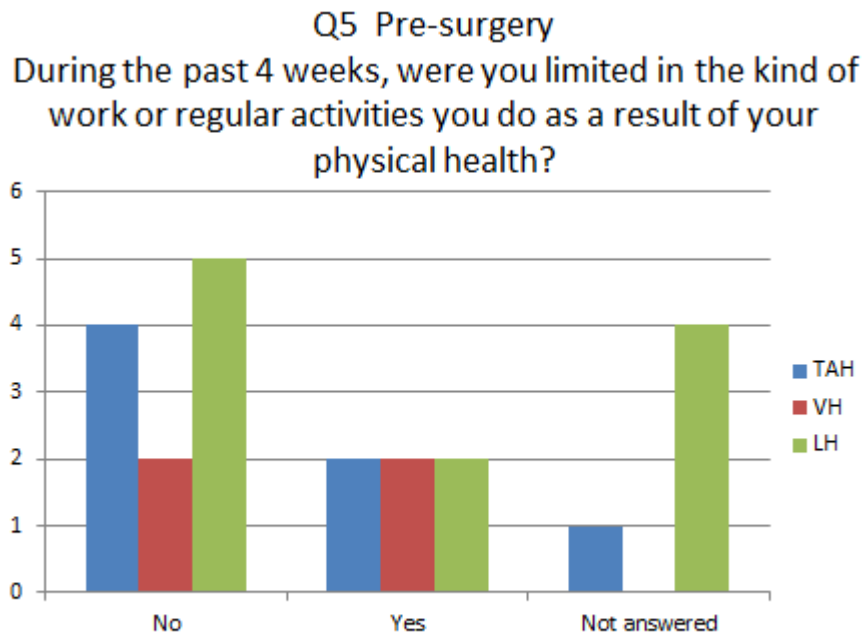


Figure 5.5



Role Functioning (Emotional) Subdomain

Figure 5.6

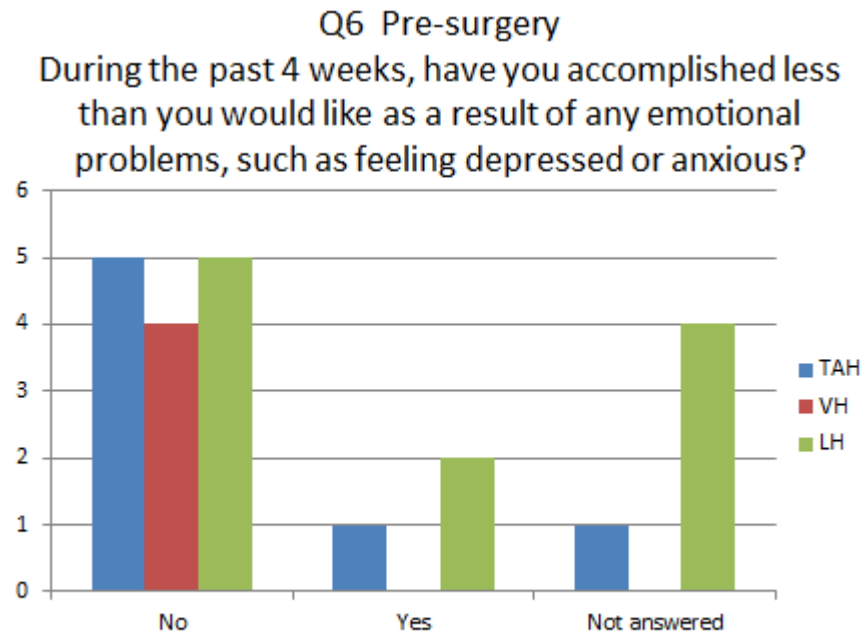
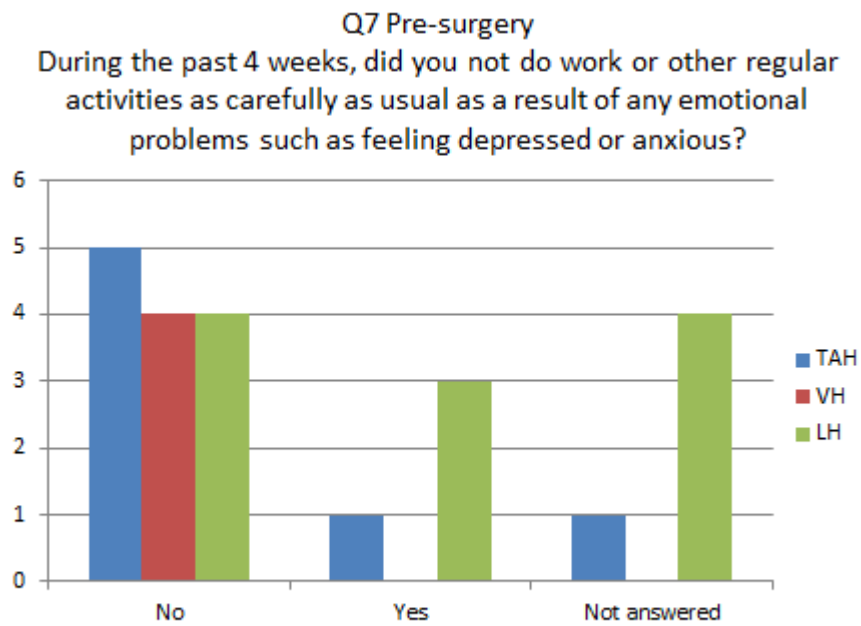
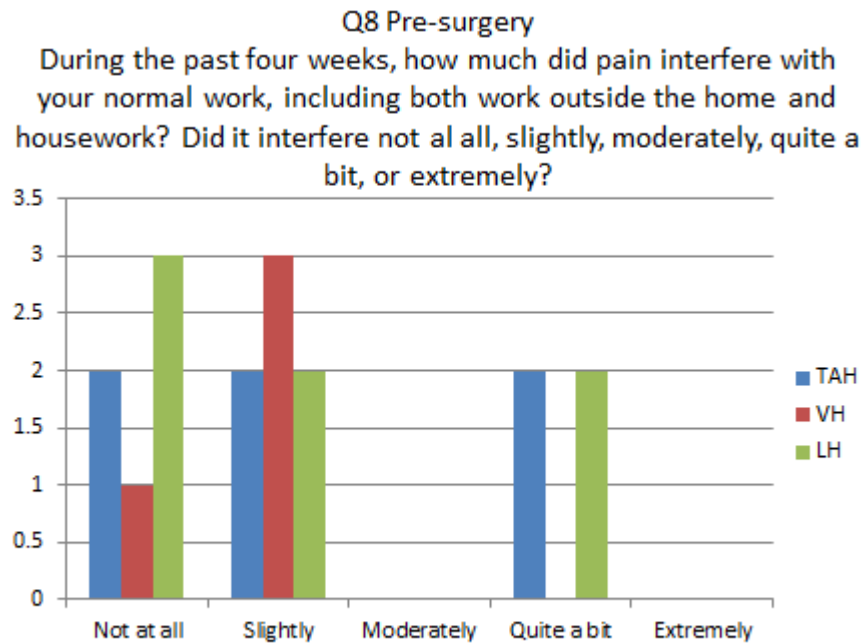


Figure 5.7



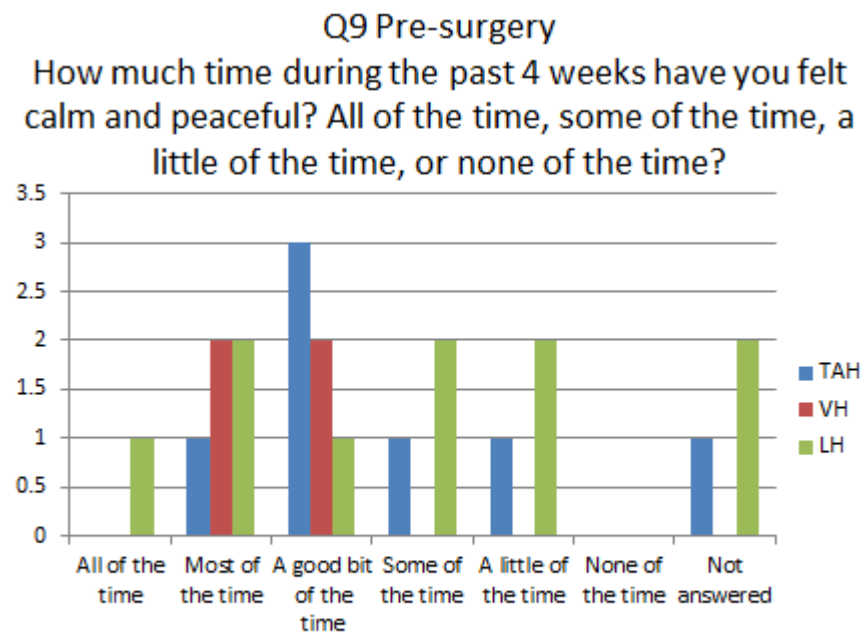
Bodily Pain Subdomain

Figure 5.8



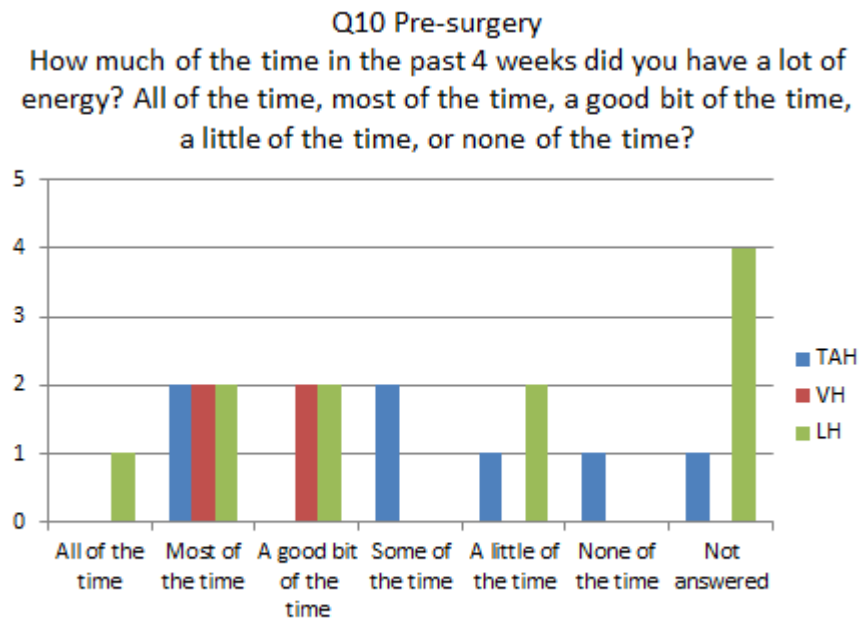
Mental Health Subdomain

Figure 5.9



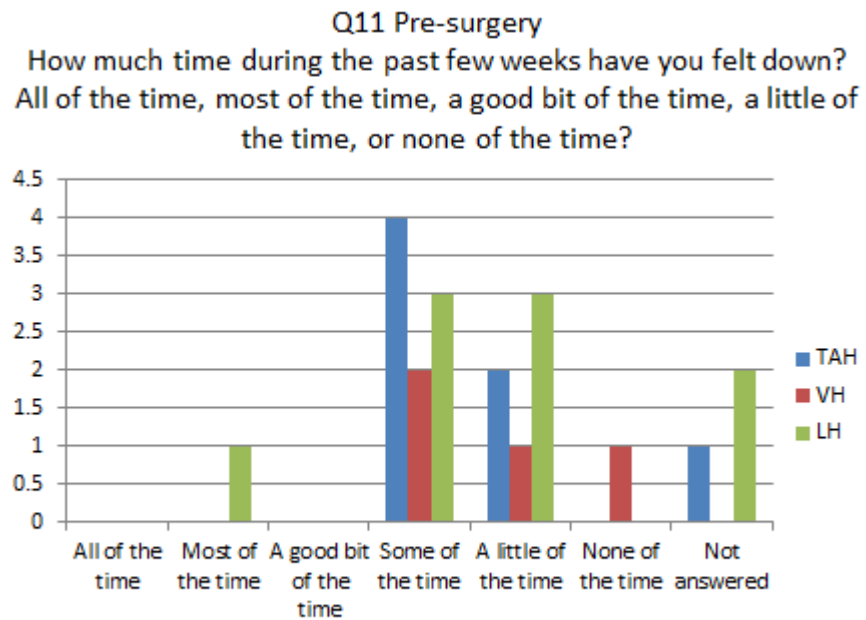
Vitality Subdomain

Figure 5.10



Mental Health Subdomain

Figure 5.11



Social Functioning Subdomain

Figure 5.12

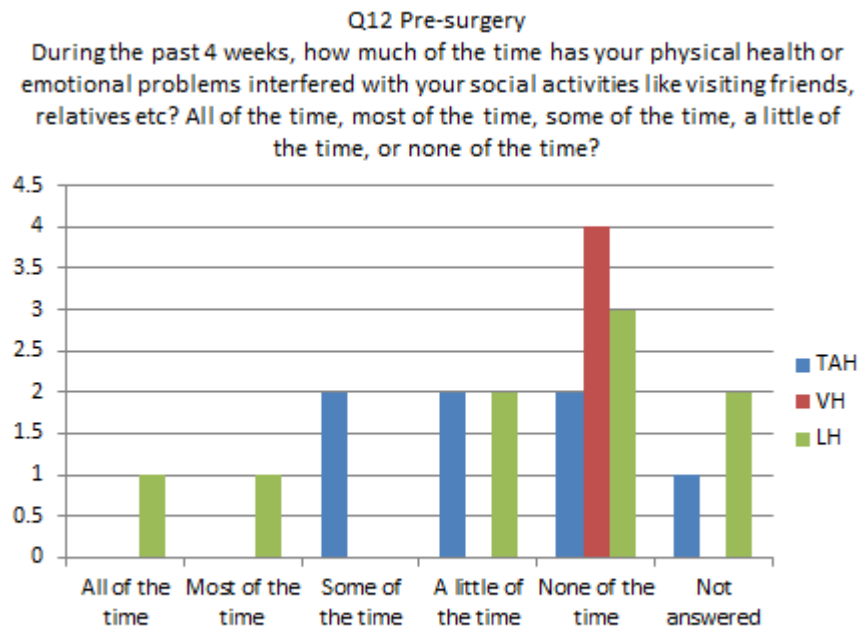


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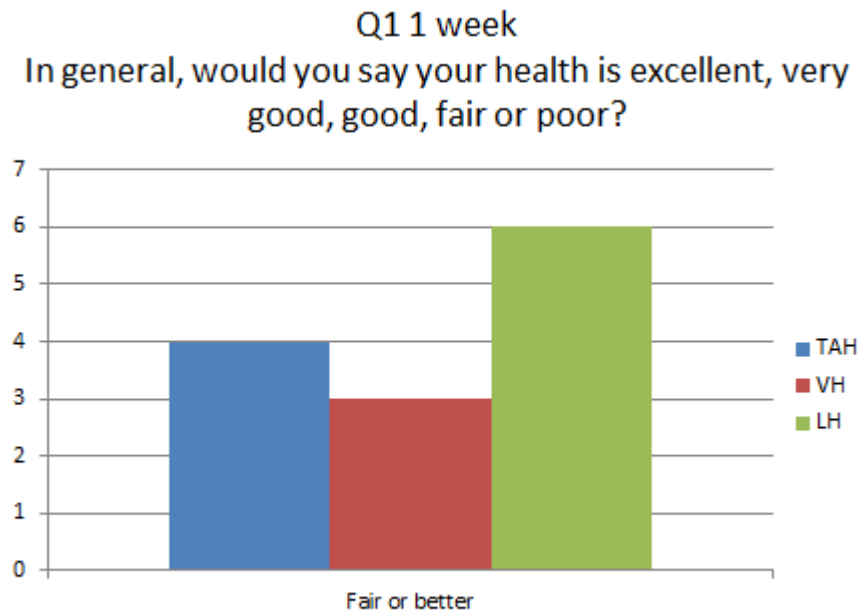


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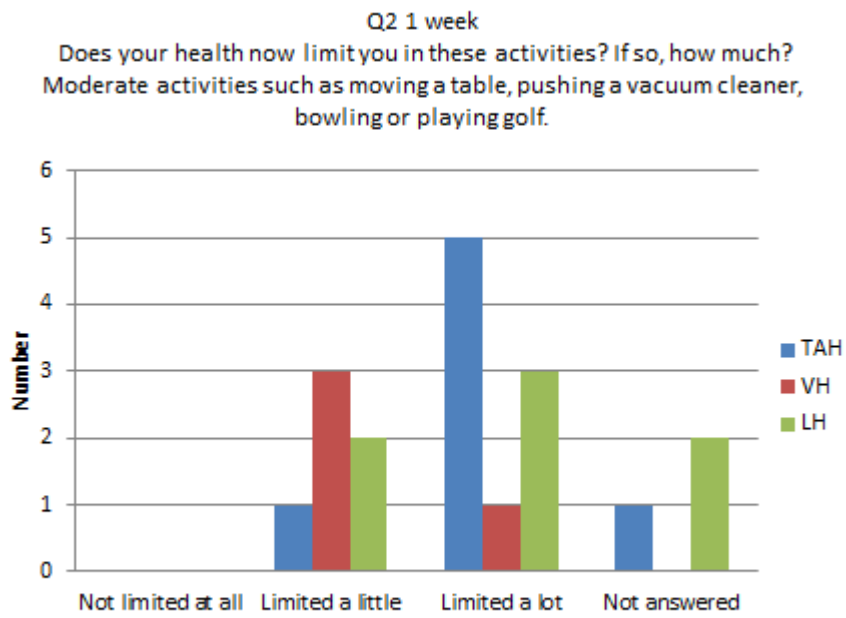


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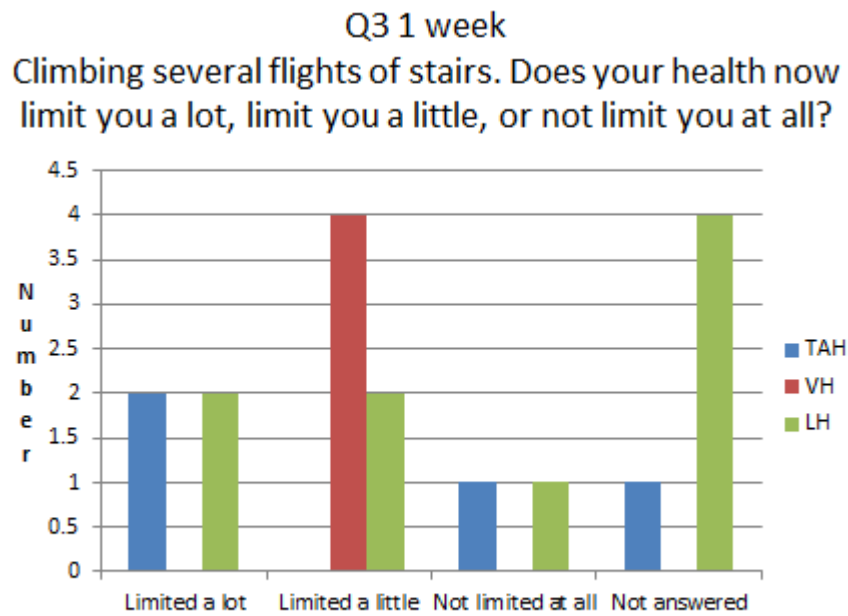


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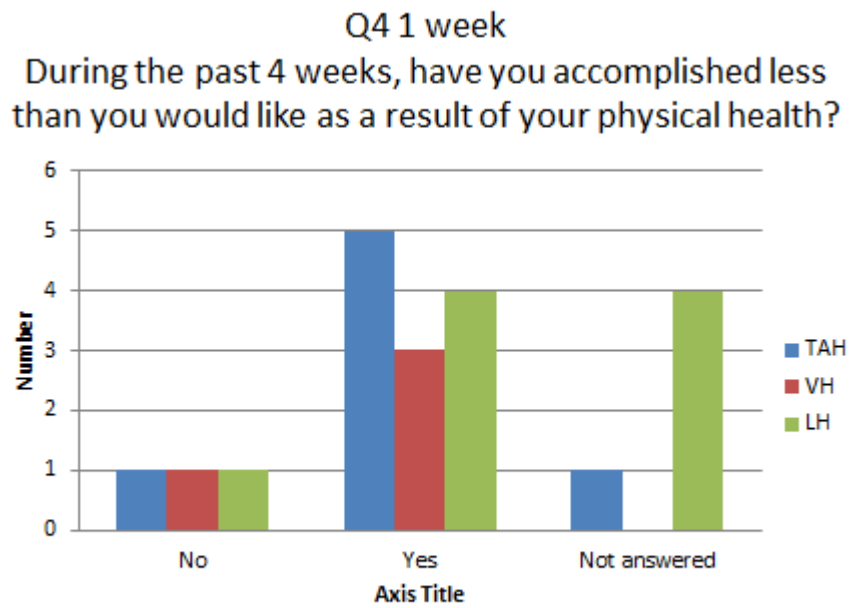


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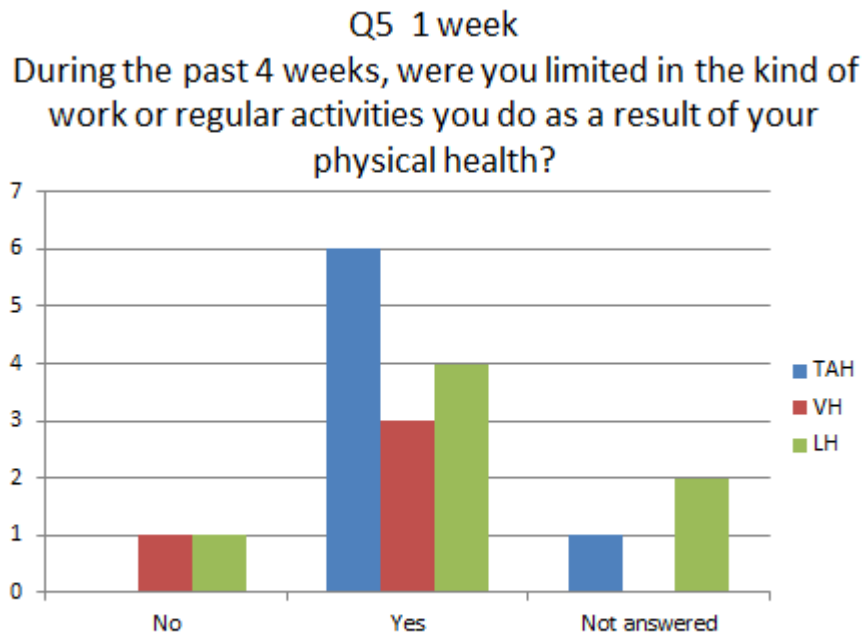


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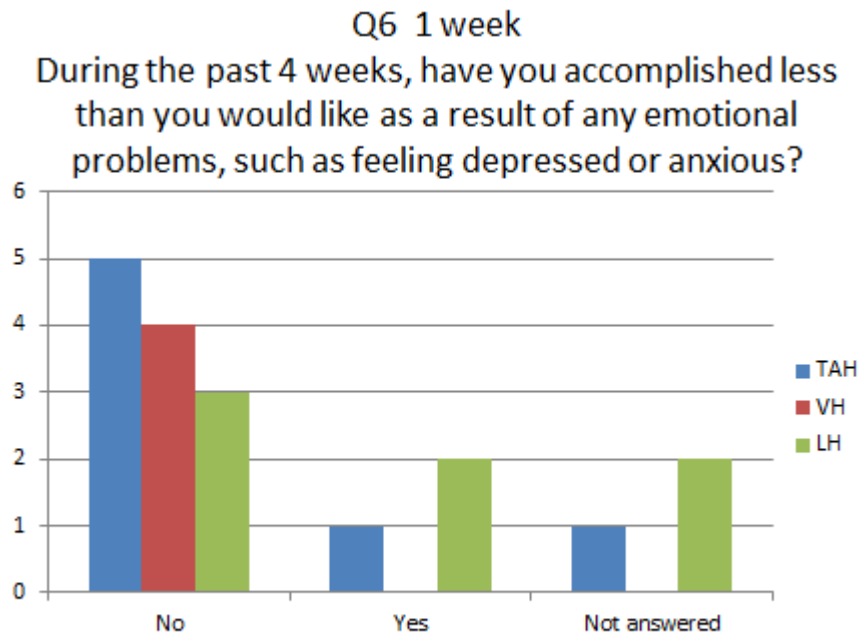


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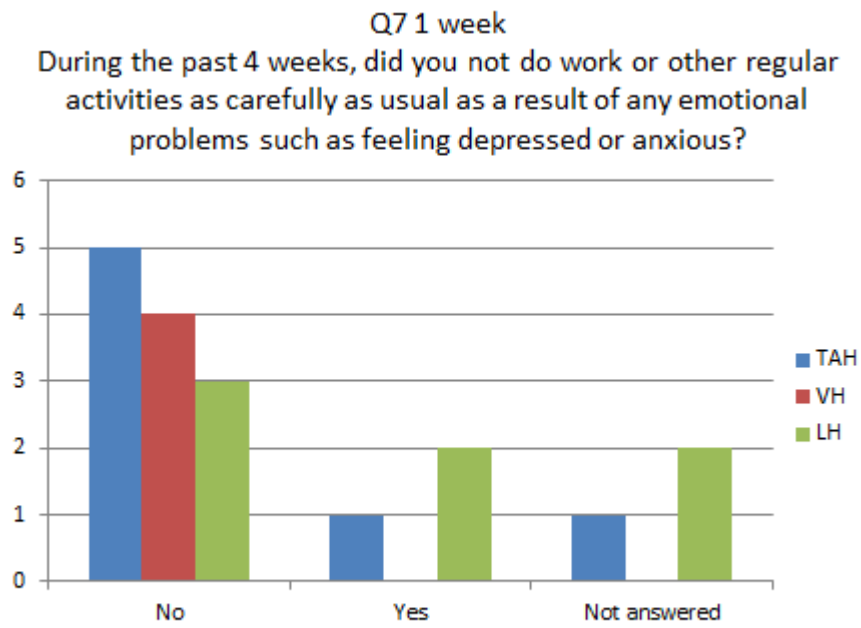


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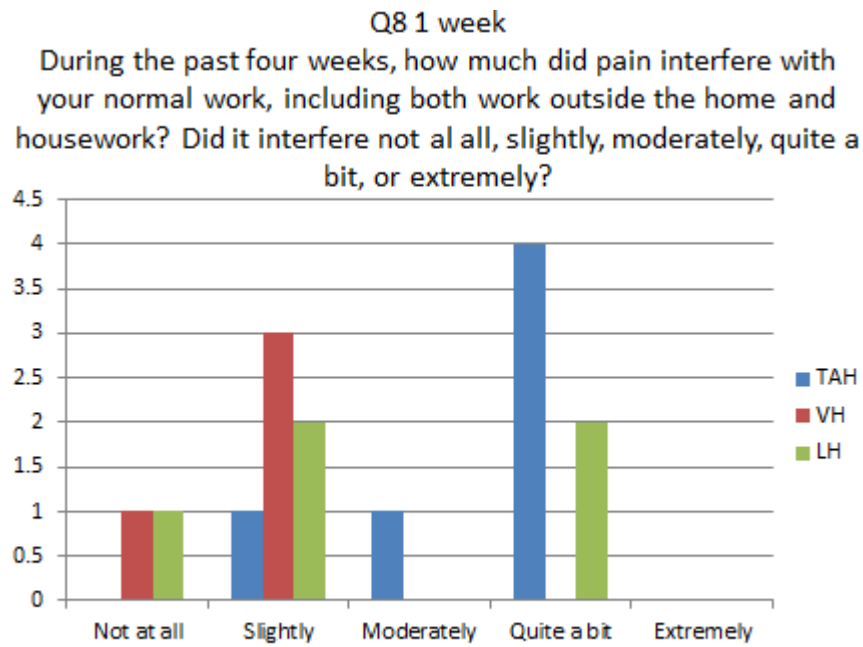


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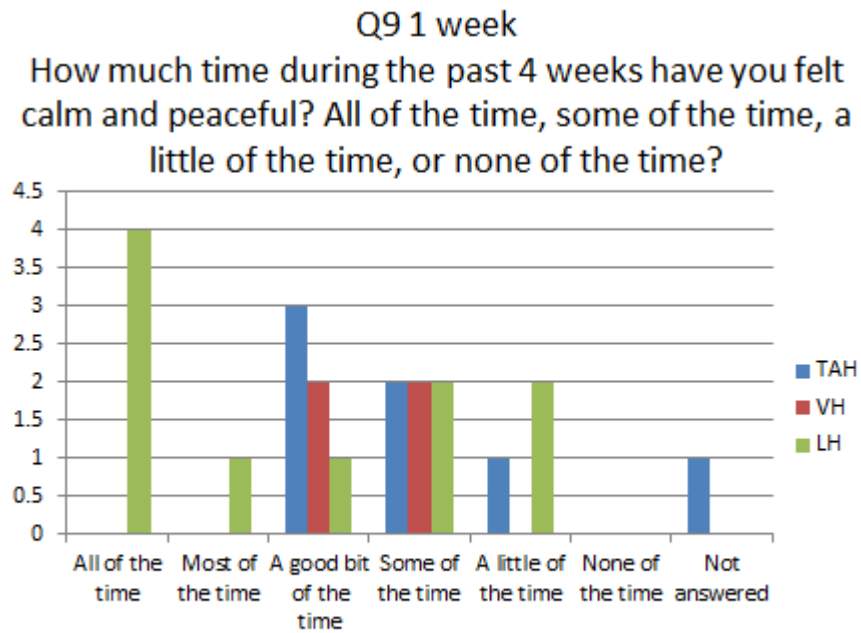


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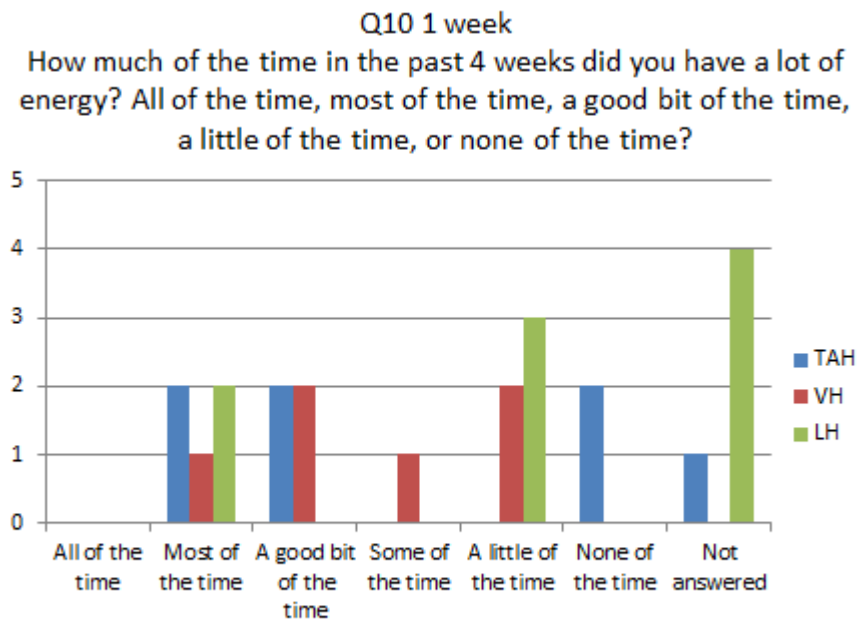


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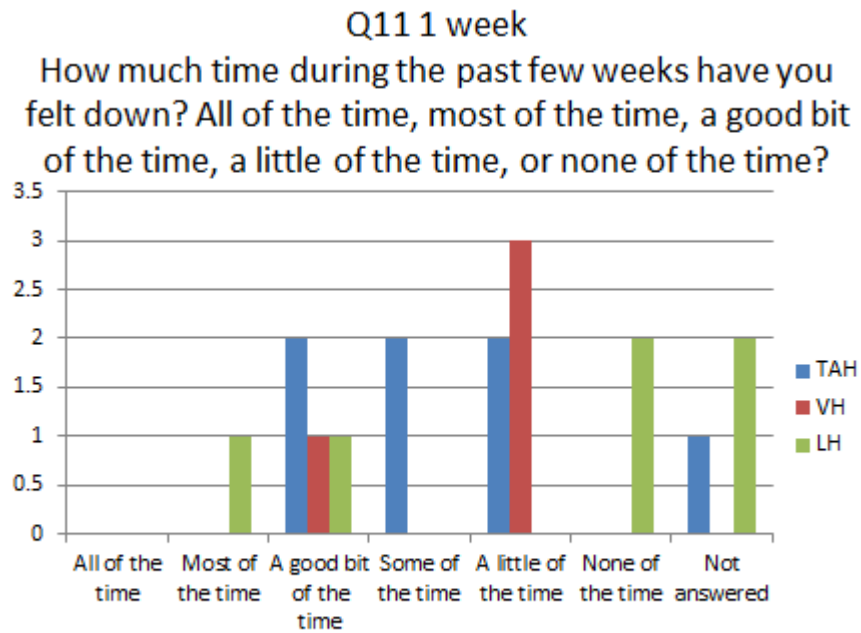


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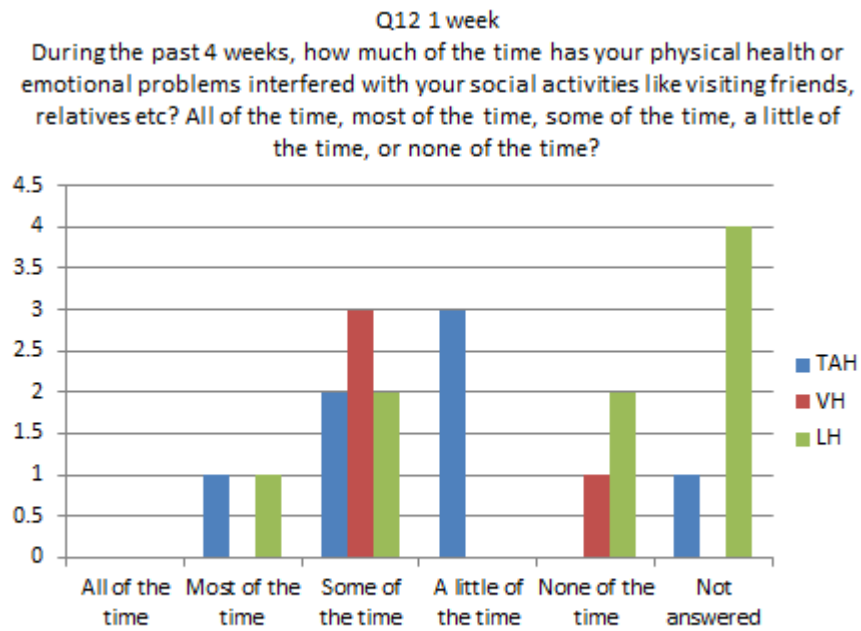


Figure 5.25



Figure 5.26

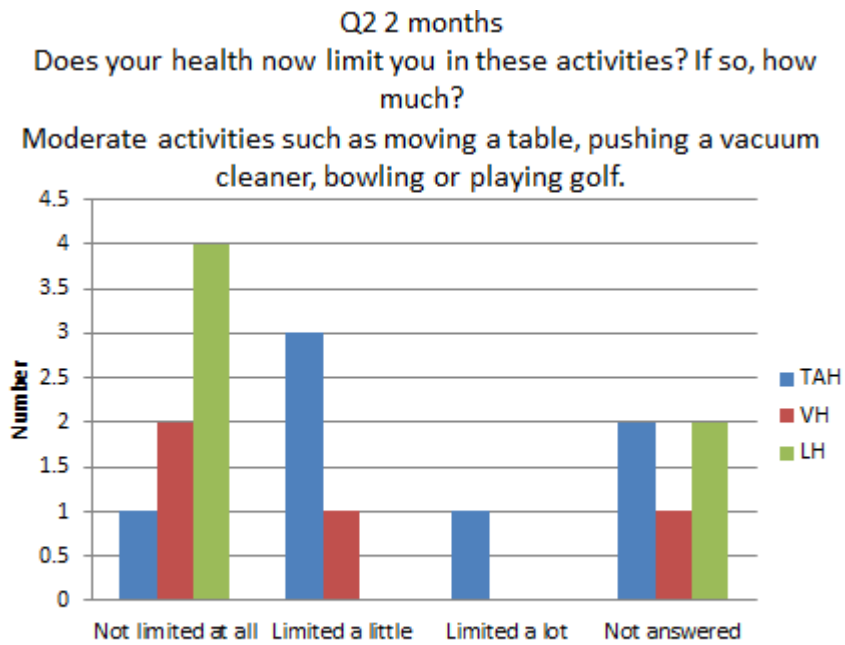


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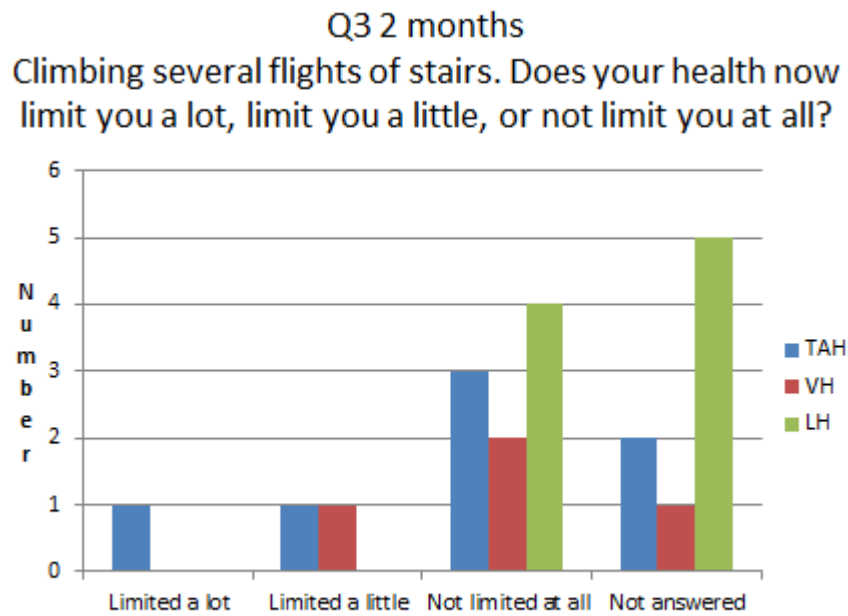


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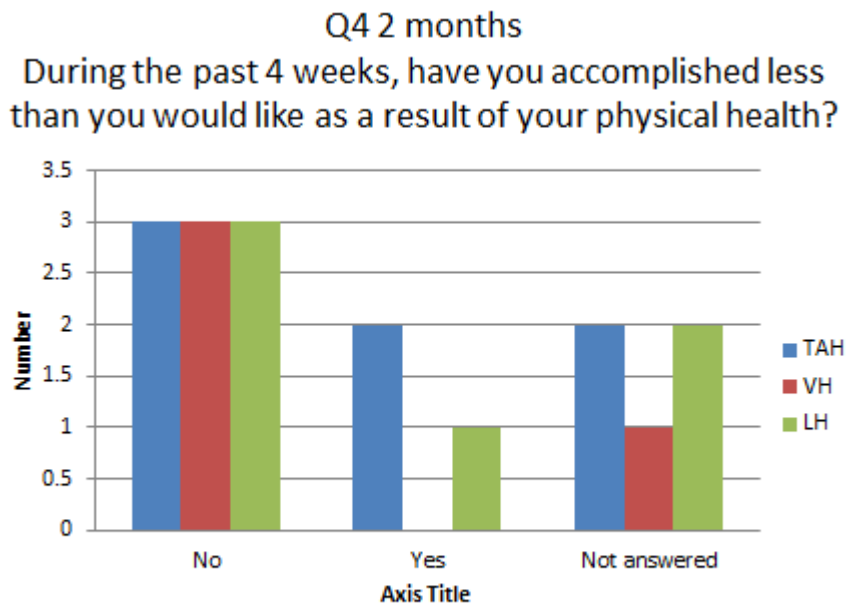


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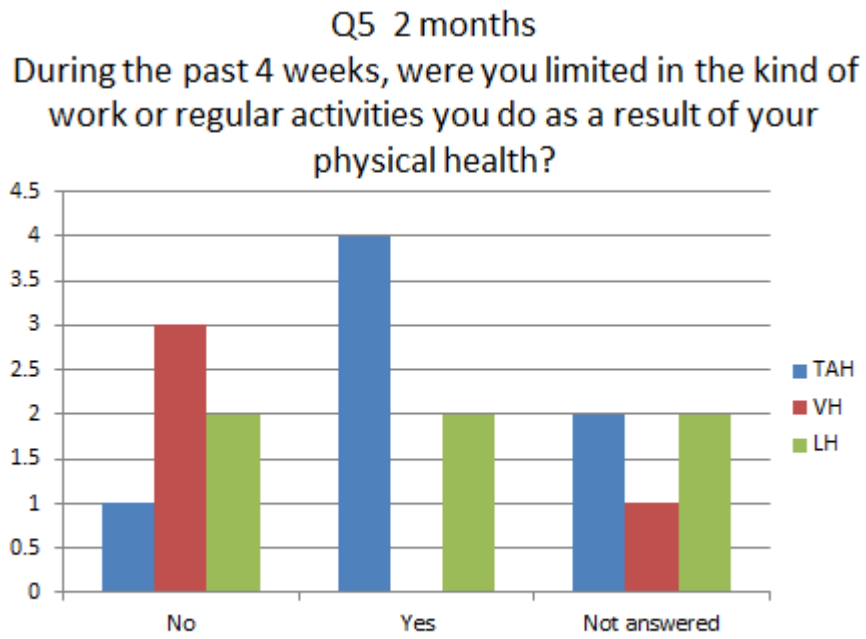


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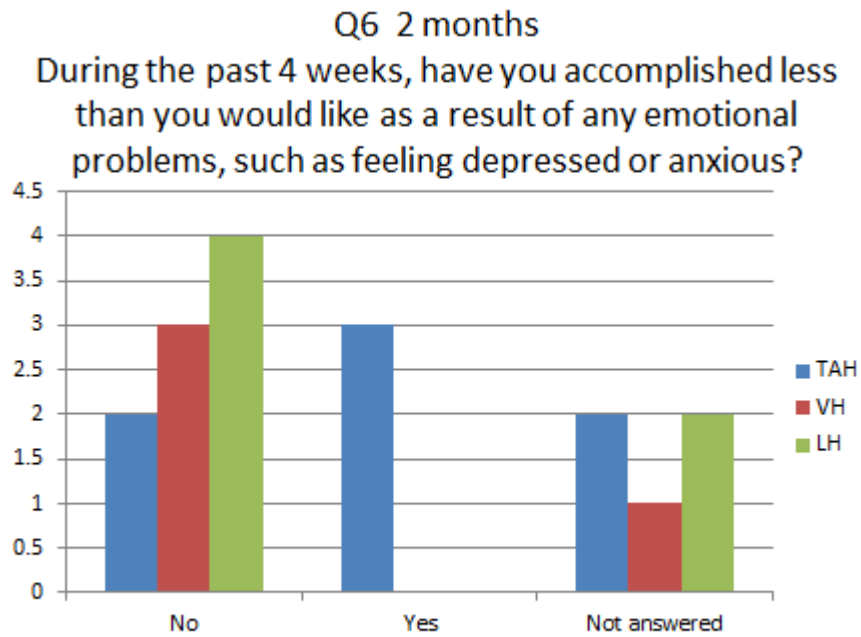


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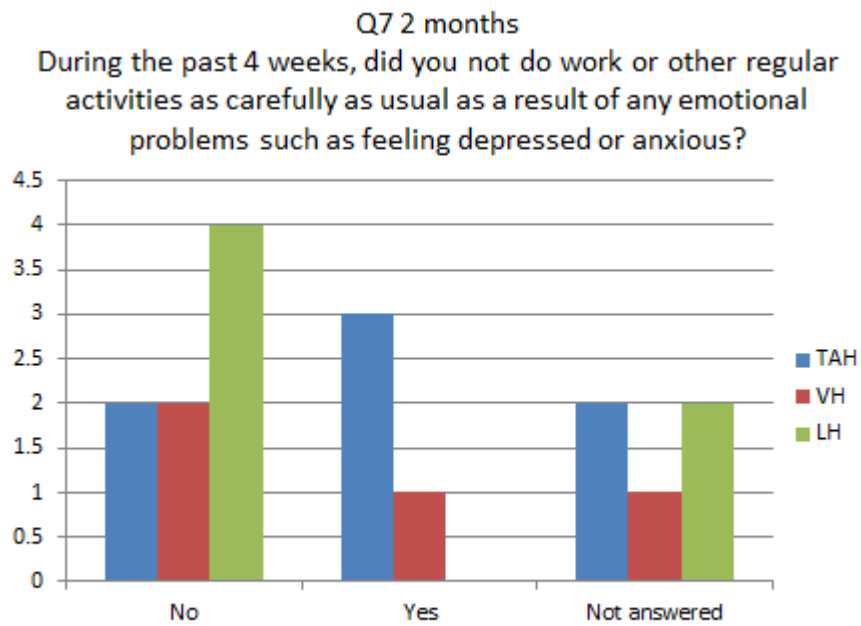


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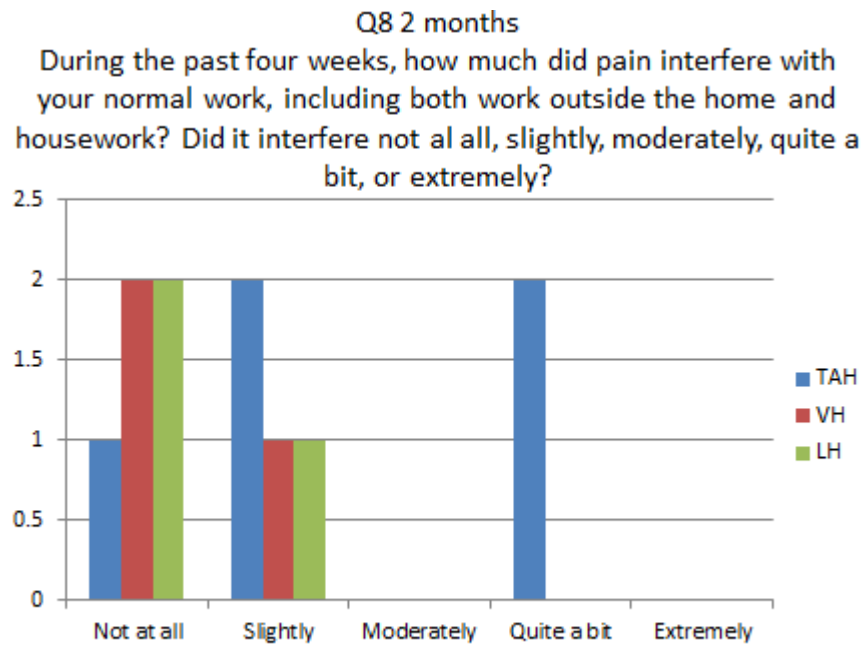


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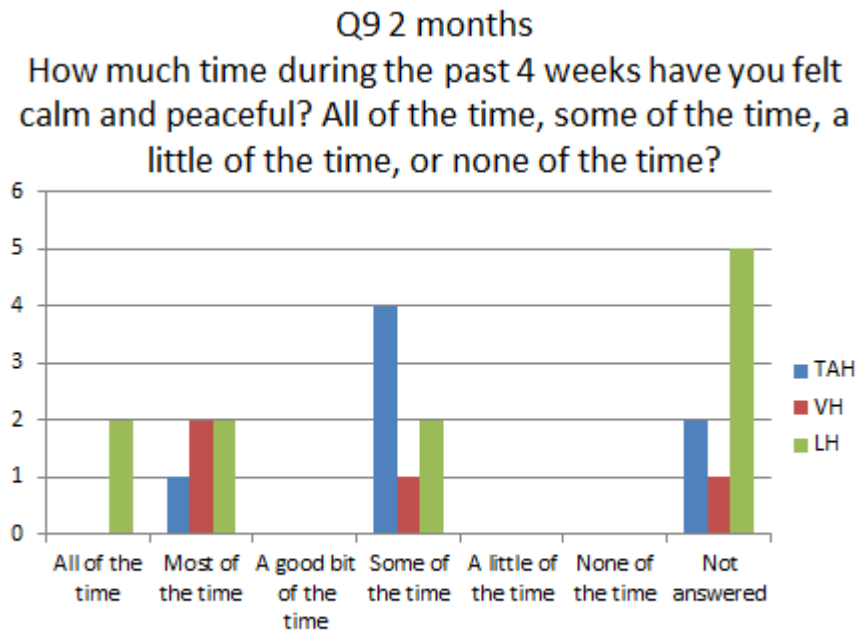


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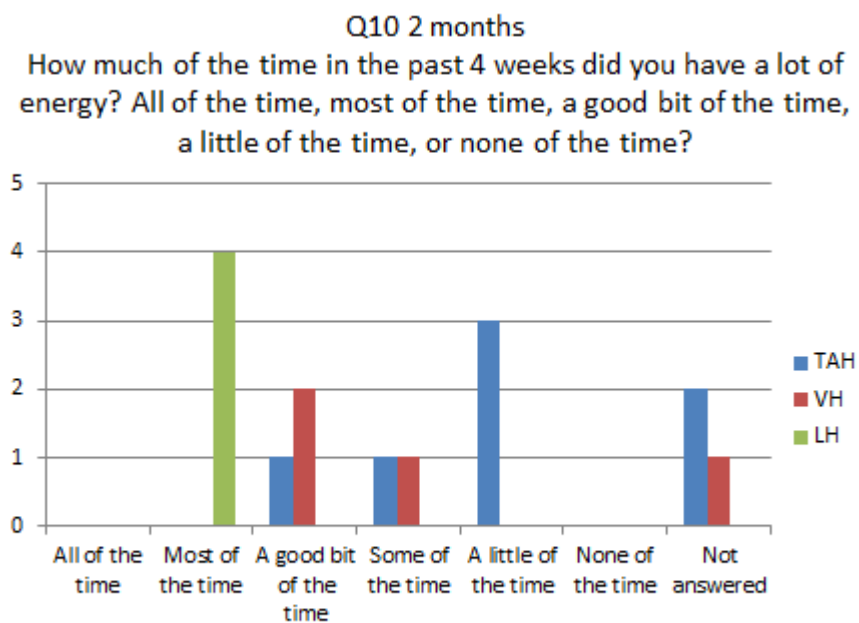


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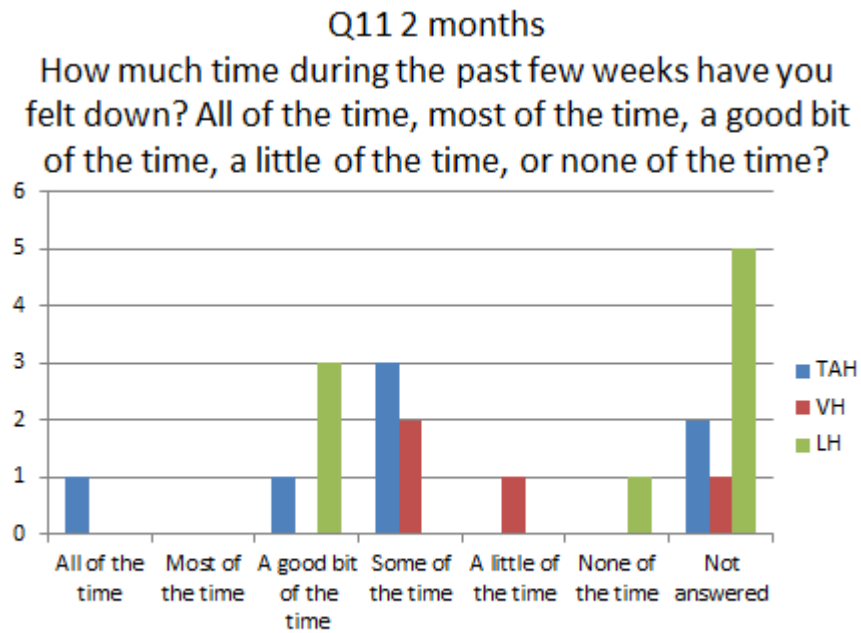


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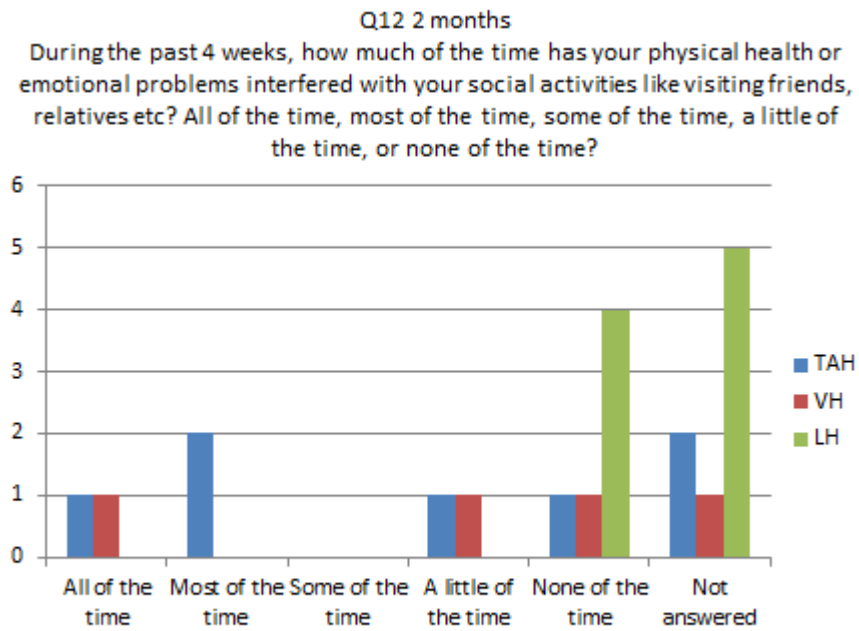


Figure 5.37



Figure 5.38

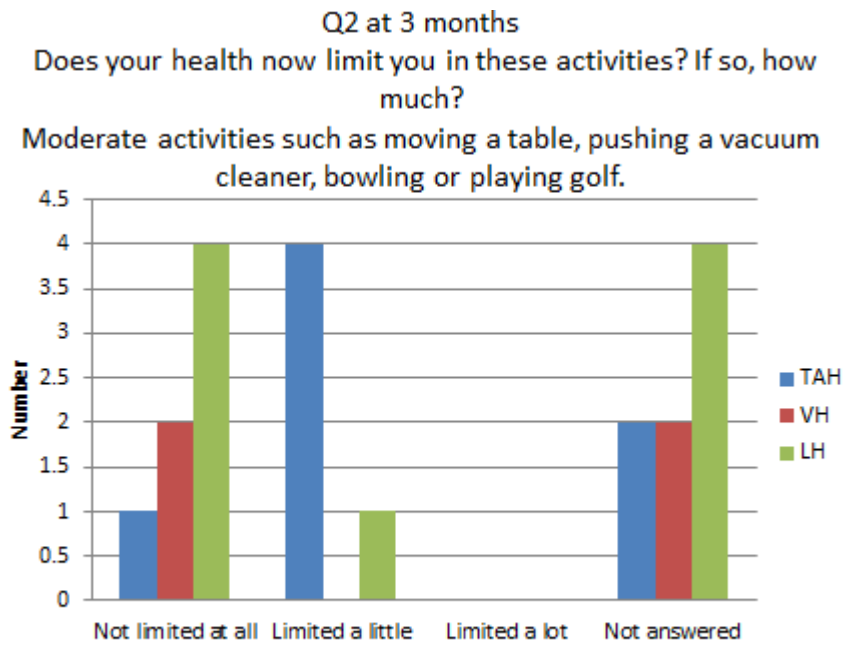


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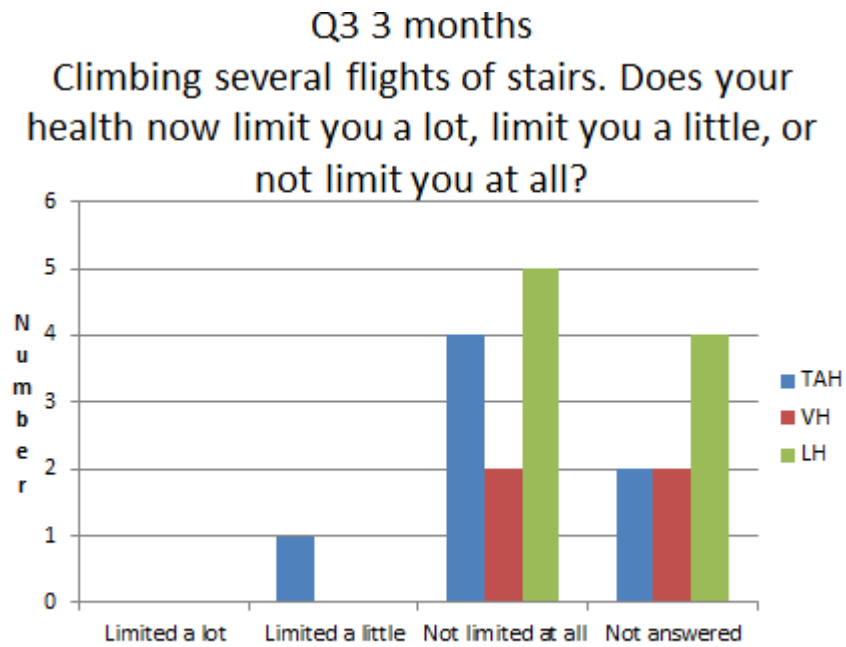


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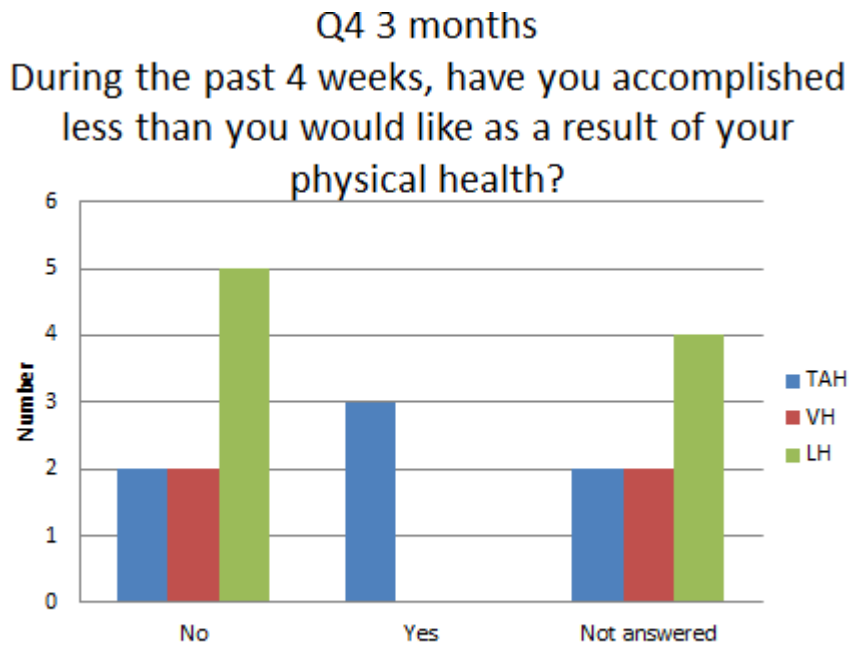


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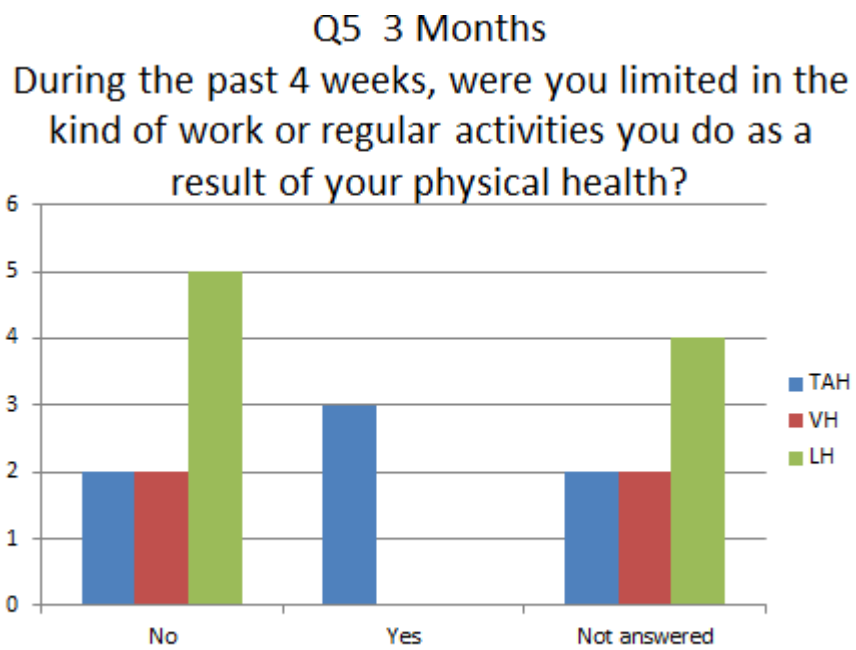


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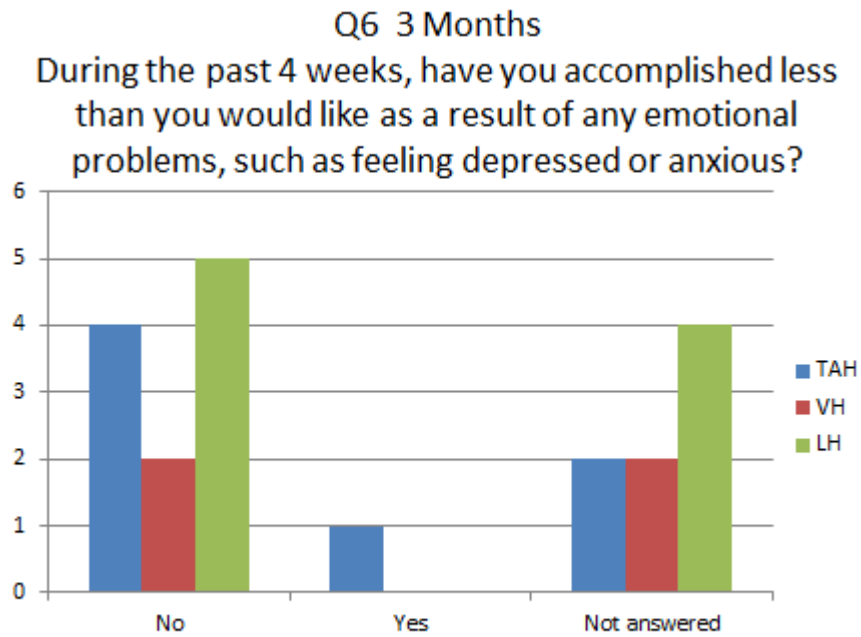


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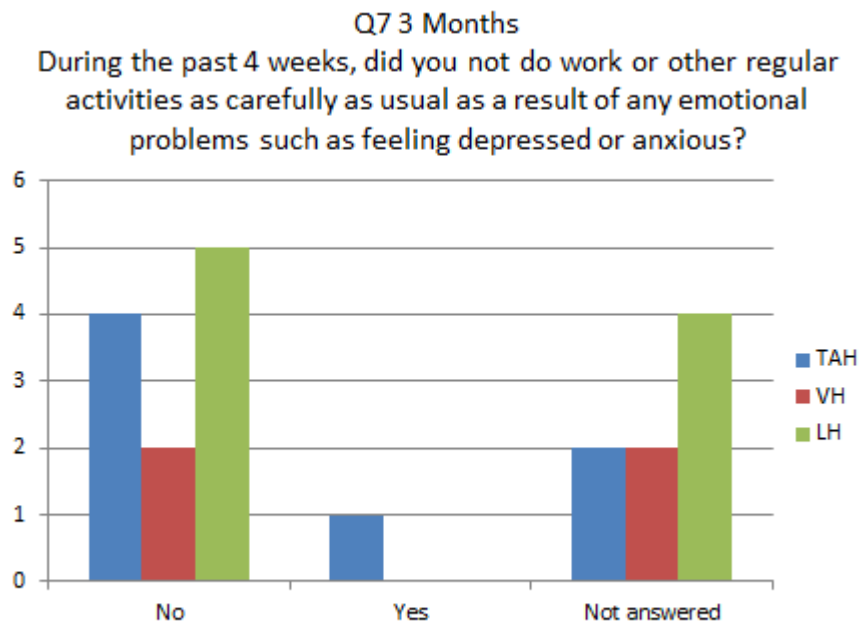


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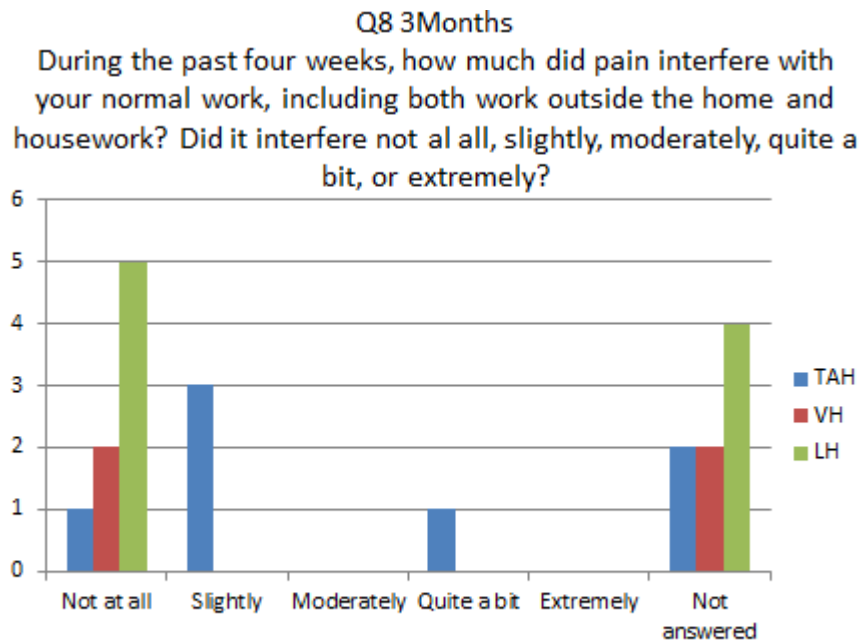


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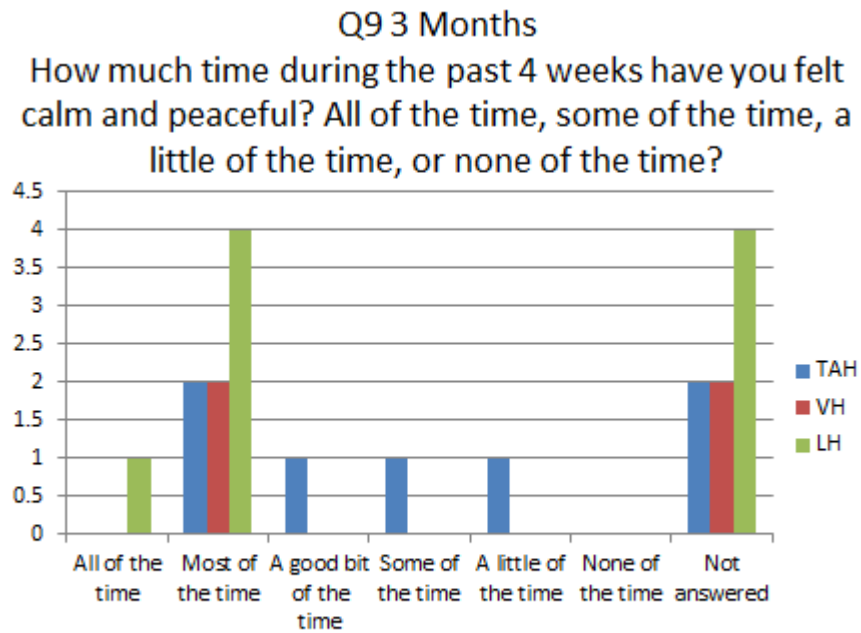


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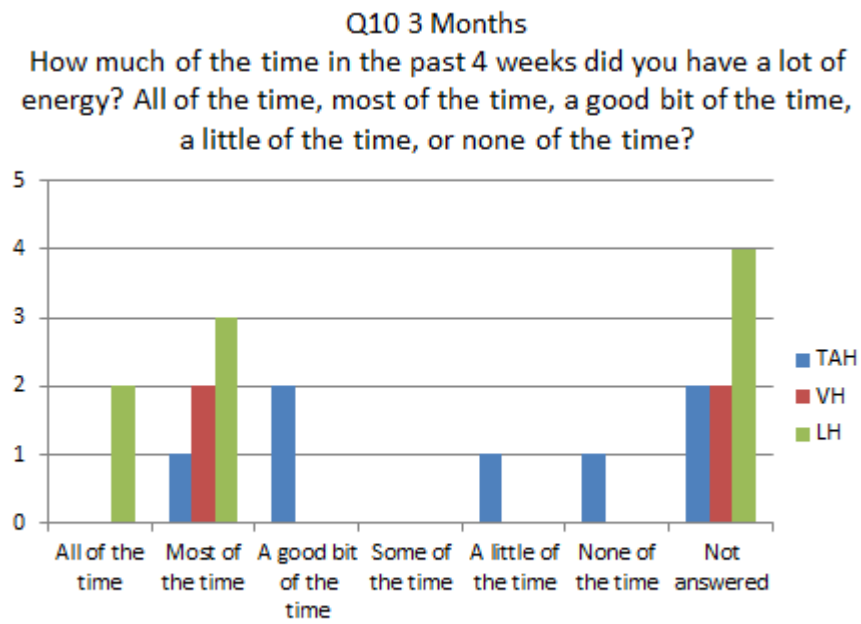


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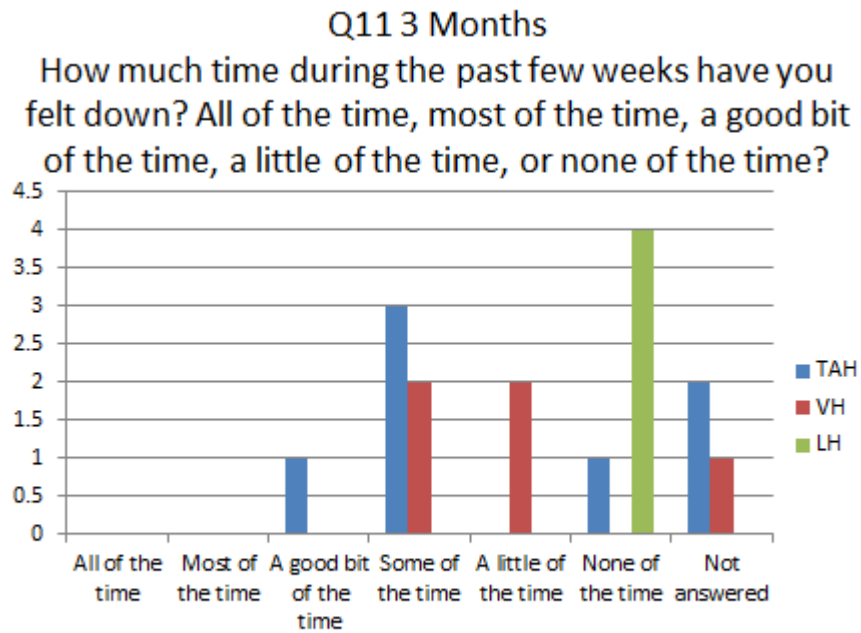
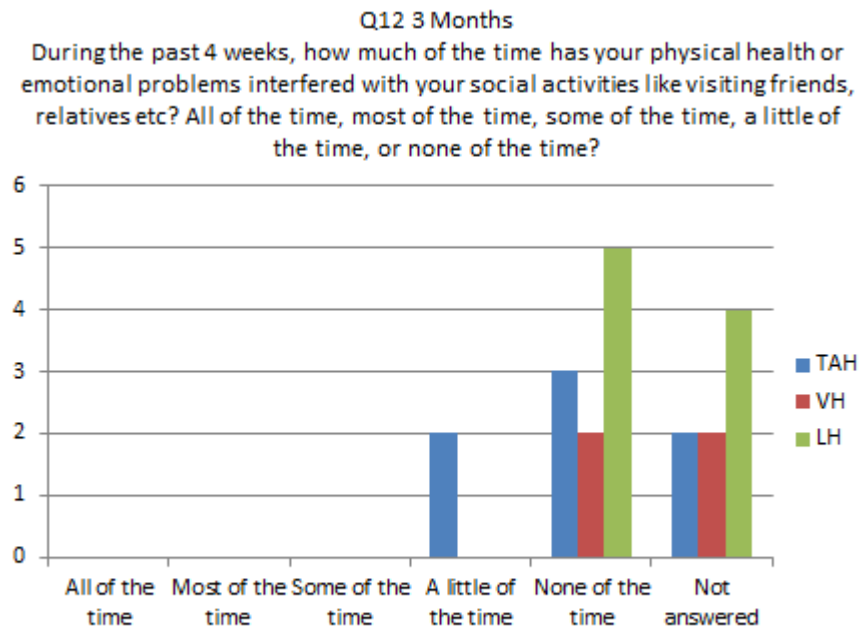


Figure 5.48



Menorrhagia Outcomes Questionnaire (Short Form)

There were unfortunately more than 10% missing scores for this questionnaire. In keeping with the instructions for analysis, the questionnaire results are not valid for statistical analysis with more than 10% missing values.

I have analysed the scores only to learn the statistical methodology. In order to analyse the menorrhagia questionnaires, the scores need to be converted around a mean of 0 called a Z score. This is then converted into a T score which is the Z score multiplied by 10 plus 50 so that there is a mean around 50. A standard deviation of the T score is then 60. The T and Z scores are useful to compare means across organisations or populations and are the standard way of presenting this data. If the T score of a population is above 50 then that population is above average. The results have not been taken into account for this questionnaire in this study, hence are not to be used in any interpretation. Tables 5.5 and 5.6 show the total outcome and quality of life/satisfaction scores in Z and scores. There was no significant difference in the change of global quality of life score before and after surgery according to route of surgery (table 5.7), or in the total outcome score at 3 months (table 5.8).

Table 5.5

Total Outcome scale scores

Participant	Route	Mean Z score	Mean T score (z x10) +50
1	TAH	Missing	
2	VH	2.235	72.35
3	VH	Missing	
4	TAH	1.823	68.23
5	TAH	1.588	65.88
6	LH	1.353	63.53
7	LH	1.176	61.76
8	TAH	1.118	61.18
9	VH	Missing	
10	TAH	1.235	62.35
11	LH	Missing	
12	LH	1.235	62.35
13	LH	1.471	64.71
14	VH	0.765	57.65
15	LH	Missing	
16	VH	Missing	
17	TAH	Missing	
18	TAH	Missing	
19	LH	1.118	61.18
20	LH	0.941	59.41

Table 5.6

Quality of Life/Satisfaction scale scores

Participant	Route	Mean Z score	Mean T score (z x10) +50
1	TAH	Missing	
2	VH	2.583	75.83
3	VH	Missing	
4	TAH	2.583	75.83
5	TAH	2.083	70.83
6	LH	1.583	65.83
7	LH	1.417	64.17
8	TAH	1.5	65
9	VH	Missing	
10	TAH	1.75	67.50
11	LH	Missing	
12	LH	1.583	65.83
13	LH	2.083	70.83
14	VH	1.083	60.83
15	LH	Missing	
16	VH	Missing	
17	TAH	Missing	
18	TAH	Missing	
19	LH	1.083	60.83
20	LH	1.0	60

Table 5.7

ANOVA of mean change in global evaluation of symptoms before and after surgery in route of surgery categories.

	F Value	Sig
Global evaluation	0.500	0.622

Table 5.8

ANOVA for mean T scores by route of surgery

Summary outcome	F Value	Sig
Total outcome scale	0.531	0.605
Quality of Life/Satisfaction scale	1.227	0.338

Discussion

The EQ5 questionnaire showed an improvement in health status for all groups 3 months after surgery as compared to before surgery. This is to be expected as we would expect the negative affect of heavy menstruation to have been relieved by the hysterectomy, regardless of route.

From the SF12, the VH group seemed to have a better quality of life pre surgery both in the physical and emotional domains. After surgery, again the VH group reported better quality of life particularly in the emotional domain. This may be because the ovaries are not usually removed as part of a VH route, whereas they are more often removed during the TAH and LH routes. We would expect that removal of the ovaries would have a negative effect on emotional wellbeing due to menopausal symptoms. After surgery, the TAH group had a lower quality of life at both 2 and 3 months. This may have been due to prolonged recovery from the larger abdominal incision. However, this study did not account for the reason for abdominal surgery which may have had an effect on the SF12 responses, such as co-morbidities requiring an abdominal approach like obesity, previous abdominal surgery or large fibroid uteri. Co-morbidities may have prolonged recovery as an independent factor to route of surgery.

We did not find a significant difference in the total outcome scores or global evaluation before surgery and at 3 months by the Menorrhagia Outcomes Questionnaire, however, this questionnaire was limited in its analysis due to the proportion of missing values, making it an unreliable result, and for this reason, it has been omitted from the conclusions. The missing scores may have been due to the long length of this

questionnaire and that it was last in the questionnaire pack. By using mean Z-score rather than total Z-scores, the effect of missing data items can be minimised, however, this is based on 10% or less missing data, this study had more than 10% missing data.

This study was also limited by the small numbers in each of the groups, as well as the missing data from incomplete or lack of questionnaire responses at different time points. It may have been that only those who were recovered well enough completed the questionnaires, or conversely, those who were recovered had returned to normal activities and were too busy to complete the questionnaires. Missing values have been reported in the literature such as the validity study for HR-QoL (127), who reported a high number of missing values which was similar to an Australian study validating the SF-12 in a heart and stroke population of 22%. They reported a higher chance of incomplete questionnaires from females, older people, those who were less educated and those patients who had stayed in hospital longer or were admitted as an emergency. Moreover, there was a higher rate of missing values in the health concepts role-emotional and role-physical items, which was also similar for the SF-36 (131). The instructions for the Menorrhagia questionnaire were for use with a much older version of SPSS. Unfortunately, I could not access anyone who could give me updated advice and the author had passed away. I therefore had a protracted analysis where I had to learn how to change scores into T and Z scores using statistical methodology. Due to the time lapse between analysing the questionnaire data and collecting the data, there was no opportunity to collect the missing data from participants. In addition, the ethical approval did not cover gaining missing data so long after the study (see chapter 8). In addition, there were a large number of questionnaire items which the participants may have felt

was onerous to complete. The Menorrhagia questionnaire was last in the pack and this may be why it had the most missing values.

Missing data in health status and quality of life questionnaires is a known problem. The validity study for HR-QoL (127) reported a high number of missing values which was similar to an Australian study validating the SF-12 in a heart and stroke population of 22%. They reported a higher chance of incomplete questionnaires from females, older people, those who were less educated and those patients who had stayed in hospital longer or were admitted as an emergency. Moreover, there was a higher rate of missing values in the health concepts role-emotional and role-physical items, which was also similar for the SF-36 (127, 131).

Conclusion

By the EQ5 and SF12 questionnaires, the VH group had least effect on quality of life by heavy menstrual bleeding pre-surgery and by the surgery post-surgery, particularly in the emotional domain. Quality of life was reported as lowest for the TAH group at 2 and 3 months post-surgery.

Chapter 6

Anxiety and surgery; A validated questionnaire survey to women who had a hysterectomy

Mechanisms that affect recovery

There are a range of mechanisms by which psychological variables could affect recovery after surgery. Variables which have been found to influence the outcome of surgery include emotional states (fear, depression, stress, a sense of hopelessness), personality traits (trait anxiety, locus of control, coping), and physiological parameters (132). This chapter studies the anxiety levels in the women undergoing the three routes of hysterectomy.

Anxiety

Surgery is associated with significant patient anxiety (86, 133, 134) and behavioural changes which have been shown to have an effect on recovery (135, 136). It is known that the majority of patients who have been admitted for elective surgery experience pre-operative anxiety. This is greater in day case patients, particularly in women. Negative emotions such as anxiety can enhance pain sensations (137). There have been differing associations of level of anxiety and post-operative recovery. In some studies, low as well as high levels of anxiety have been found to lead to worse recovery outcomes, with medium levels of anxiety being associated with the best recovery (138). Other studies

have found a linear relationship with low anxiety associated with a better recovery (132). All pre-operative anxiety has been found to predict the level of post-operative pain (87). The State Trait Anxiety Inventory (STAI) is a validated questionnaire to measure anxiety in adults. It distinguishes between the temporary condition of 'state anxiety' and the more general and longstanding quality of 'trait anxiety' and depression (139). Anxiety measured by the STAI in patients who had a laparoscopy for pelvic pain correlated with the length of time patients felt they were completely cured and free of complaints independently of the laparoscopy findings (140). A longitudinal study of the impact of anxiety and depression on pain experience over time after major gynaecological surgery found that pre-operative anxiety was predictive of anxiety on day 2 after surgery. Moreover, it reported anxiety levels on day 4 in one third of patients reaching psychiatric proportions (141). Levels of pre-operative psychological morbidity are found to be higher in women who have a hysterectomy as compared to the general population (142, 143).

Initially, it was shown that there were negative associations between anxiety levels and endocrine changes in surgical patients (144), however in a more recent study, a preparatory video showing realistic aspects of the perioperative period prior to cardiac surgery did reduce blood cortisol, ACTH, prolactin and noradrenaline levels (145). Reducing anxiety has been defined as one of the principles of conducting a pre-anaesthetic consultation (146).

Personality variables of denial, fear and aggressiveness have been shown to be associated with recovery and responses to pre-operative preparations (147). For example, a high

mortality rate has been shown in patients who were depressed before cardiac surgery (148). Stress has been linked to the slower healing of wounds through psychoneuroimmunological mechanisms (88).

The STAI (Stait Trait Anxiety) questionnaire (appendix 16)

The stait trait anxiety questionnaire (STAI) is used to measure anxiety. There are three forms of the questionnaire, X, Y and STAI children. The STAI X was the original questionnaire to measure anxiety in adults and the current updated version is the STAI Y. The STAI children is used to measure anxiety in children. The STAI Y requires at sixth grade reading level and contains four-point Likert scales, the scales are positively correlated with anxiety scored from 20 to 80. The higher the score, the greater the anxiety (139). The questionnaire is divided into two parts, each with 20 questions. Each part looks at two types of anxiety; state (S) and trait (T) anxiety and the overall anxiety level. It is estimated that 10 minutes is required for an adult to complete the questionnaire. It helps researchers to distinguish between the feelings of transient anxiety from depression (149). Some questions are reverse scored because they test for the absence of anxiety. Responses for the S-Anxiety scale assess intensity of current feelings with answer options of not at all, somewhat, moderately so and very much so. The T-Anxiety score is that of general feelings with answer options of almost never, sometimes, often and almost always. Higher scores mean more anxiety and they are used to compare anxiety trends at various time points for the same population or to compare different populations. STAI does not measure overall anxiety.

Validity

The STAI has been shown to have construct validity against other assessments of anxiety, such as between Panic Disorder and right-hemisphere brain over activation (150), and the

STAI-trait and STAI-state correlated with the Anxiety Sensitivity Index (151) and with the Conjugate Lateral Eye Movement Test (152).

Concurrent validity with other scales that measure anxiety has been demonstrated with the Anxiety Scale Questionnaire (ASQ) (153) and Manifest Anxiety Scales (MAS) (154).

Reliability

The test-retest reliability has been demonstrated using 29 male undergraduate students two weeks before and after a stressful social analogue situation (155) . The state anxiety increased but the trait remained constant. This correlated with the STAI scores of 0.54 and 0.40 for state and 0.86 and 0.86 for trait.

Feasibility

The STAI is inexpensive and can be used in a multitude of scenarios including research, psychometric testing such as interviews and clinical scenarios. It can be administered on mass and has less questions than other measures of anxiety (ASQ has 40 questions and the MAS has 50). Although the STAI has been adapted into 48 languages, we only used it for English readers due to financial constraints of translation.

Aim

To study anxiety before a hysterectomy and at 1 month and 3 months of recovery after surgery.

Methodology

The STAI questionnaire was given to the qualitative hysterectomy group at the interview before surgery, one week after surgery and then 3 months after surgery. The STAI was in paper form marked with the participant trial number and handed to the participant to

complete in their own time. A self-addressed envelope was provided for the participant to post the completed questionnaire back.

The data from the questionnaire was inputted manually into a Statistical Package for Social Sciences, version 16.0 (SPSS, Inc., Chicago, Illinois, USA.) database and analysed for mean STAI for the state and trait sections at each time point. Due to missing data, we were not able to compare the mean STAI for participants at each time frame. Analysis was done using analysis of variance (ANOVA) as the statistical test in order to measure the means of more than 2 groups or time points. The ANOVA gives a real effect comparison means of the groups as a F value and the significance is tested and presented as a P value; where a $P > 0.05$ is statistically significant.

Results

Demographics

The study group comprised of the qualitative group. They were all women who were having a hysterectomy for benign gynaecology problems via the abdominal, vaginal or laparoscopic routes.

Table 6.1: Demographics

Route of hysterectomy	Number of participants
Abdominal	7
Vaginal	4
Laparoscopic	9

The mean (table 6.2) STAI-state score pre-operatively was 40 (SD 13.53) and mean STAI-trait score was 41.5 (SD 11.76). At one week after surgery, the mean STAI state score was 45.6 (SD 14.9) and the mean STAI-trait was 42.7 (SD 13.0). At 3 months after surgery, the mean STAI-state score had fallen to 31.1 (SD 10.7) and the mean STAI-trait was 32.7 (SD 11.8).

Table 6.2: Mean STAI scores at time points

Time point	Mean STAI-state (SD)	Mean STAI-trait (SD)
Pre-surgery	40 (13.53)	41.5 (11.76)
1 week post-surgery	45.6 (14.9)	42.7 (13.0)
3 months post-surgery	30.1 (10.7)	32.7 (11.8)

STAI versus route at the different time points

Anxiety levels using STAI were compared by route of hysterectomy using a one way between groups analysis of variance (ANOVA). Where a significant difference using a value of 0.05 was seen, multiple comparisons of means after post hoc tests using Welsh and Brown-Forsythe were used to identify where the difference among the groups lay.

Pre-operative STAI versus route of hysterectomy

Pre-operatively, there was very little difference in the state anxiety scores according to route of hysterectomy. Question 6 showed a small significance towards the TAH group of 0.375 and question 12 towards the LH group at 0.217. In the trait questions, pre-operatively there was more anxiety in the LH group in questions 22 at 0.17, question 28 at 0.301 and question 30 at 0.125. The VH had significant values for questions 29 at 0.244 and question 32 at 0.182. At 1 week post operation, the state values did not show any trends between groups apart from the VH group, where there were no significantly increased state values apart from question 1 at 0.22. Table 6.3 shows the significant stait values at 1 week post operation.

Table 6.3: Significant ANOVA by question and route of hysterectomy for STAIT anxiety
1 week post operation.

Question number	ANOVA value	Route of hysterectomy where mean was higher
1	0.22	VH
3	0.242	LH
4	0.062	TAH
5	0.285	LH
6	0.058	TAH
7	0.418	TAH & LH
8	0.136	LH
9	0.023	LH
11	0.392	LH
12	0.484	TAH
13	0.345	LH
14	0.220	LH
17	0.172	LH
18	0.274	LH
20	0.335	TAH

Again trait anxiety did not show any trends 1 week post operation with route of hysterectomy (table 6.4) apart from the VH group, who again did not show increased anxiety in any questions to a significant value.

Table 6.4: Significant ANOVA by question and route of hysterectomy for trait anxiety 1 week post operation.

Question number	ANOVA value	Route of hysterectomy where mean was higher
21	0.87	TAH
23	0.231	TAH
24	0.345	TAH
25	0.482	TAH AND LAH
26	0.454	LH
27	0.391	LH
28	0.260	TAH
31	0.454	TAH
32	0.371	LH
33	0.417	LH
34	0.193	LH
35	0.294	TAH
36	0.481	LH
38	0.345	LH
39	0.229	LH
40	0.442	TAH

At 3 months after hysterectomy, the TAH group showed significantly more anxiety in both the state and trait questions (table 6.5), particularly in question 19 (I feel steady), where the significant value was 0.003.

Table 6.5: Significant ANOVA by question and route of hysterectomy for state and trait anxiety 3 months post operation.

Question number	ANOVA value	Route of hysterectomy where mean was higher
STATE ANXIETY		
3	0.166	TAH
4	0.145	VH
6	0.228	TAH
8	0.225	TAH
10	0.112	TAH
11	0.315	TAH
12	0.132	TAH
14	0.132	TAH
15	0.012	TAH
16	0.166	TAH
17	0.44	TAH
18	0.228	TAH
19	0.003	TAH
20	0.219	TAH

TRAIT ANXIETY		
Question number	ANOVA value	Route of hysterectomy where mean was higher
22	0.010	TAH
24	0.302	TAH
26	0.494	TAH
28	0.228	TAH
29	0.020	TAH
30	0.494	TAH
31	0.166	TAH
32	0.029	TAH
33	0.382	TAH
34	0.209	TAH
35	0.366	TAH
36	0.191	TAH
37	0.59	TAH
39	0.31	TAH
40	0.283	TAH

Discussion

The STAI is positively correlated so the higher the score the more anxiety. In this study, we found that for both the state and trait sections, the mean scores fell at 3 months post-surgery from the pre-operative period. The state score was higher in the week after surgery, which is to be expected, although the background trait scores were not changed much in the week after surgery. Our study aligns with the published literature where the state anxiety becomes lower as recovery from surgery is achieved (156).

We saw that the total abdominal hysterectomy group had significantly higher state and trait anxiety scores 3 months after surgery than the vaginal or laparoscopic hysterectomy groups. There is no simple explanation to this and it may be associated with the increased morbidity associated with an incision through the abdominal wall and recovery from reduced core strength as a result. This could lead to longer recovery such as mobility and pain relief. It may have been that women consider an abdominal route as a more serious or bigger operation due to the visual association with a large scar on the abdomen. In my experience, women do worry about a large abdominal scar more than laparoscopic small incisions.

We know as many as 60% of patients undergoing surgery are anxious (157), and females and depressed patients in pain are particularly susceptible (86). Anxiety is attributed to uncertainty such as the thought of the unknown, severe pain, nausea and vomiting or imminent death as well lack of information (86, 158). The previous experience and personality has been shown to influence the style of coping with major life events such as surgery (159).

Trait and existential anxiety are more resistant to psychological interventions such as information giving or cognitive therapies (160), however procedure specific interventions have been shown to be influenced by psychological interventions (161).

There are limitations to this study because of the missing data due to which we were not able to follow each patient through to compare their anxiety scores at each time point. The percentage of patients where there was missing data was 40% at 3 months, and for this reason, no conclusions have been formed using the statistical analysis from this part of the data . In this study, we did not study personality types, which we know influence anxiety and coping mechanisms, however, there were not great differences in the STAI scores between patients which may suggest differing personality types. The small numbers in this study is an additional limiting factor, especially to compare the STAI scores at each time point for the differing routes of surgery.

For this part of the study, we did not perform a power calculation to assess the number required to show statistical differences in the study question, as it was designed to gain an understanding of anxiety for the qualitative interview group only.

The pre-operative questionnaires were not taken at a specific time point, so some participants may have had longer to wait for their surgery and this study cannot assess whether there is a difference in anxiety scores compared to how close the participant was to having surgery or how long they have waited on the waiting list. Waiting for surgery has been shown to be a major stressor (162). The STAI scores are not adjusted for co-morbidity and we did not take into account the socio-demographics of the participants, all of which may have influenced the scores (163).

Conclusion

The results from this part of the study show that STAI anxiety scores are increased in the period before surgery and in the immediate post-operative period, but that they drop in the recovery period after a hysterectomy. When a hysterectomy is performed by the abdominal route, the anxiety scores are higher at 3 months post-surgery as compared with vaginal or laparoscopic routes.

Systematic Review Chapter 7

Psychological Preparation for Recovery from Gynaecological Surgery

Background

There is good evidence that how people think and feel before surgery affects their recovery, such as anxiety and pain (164, 165). Negative emotions enhance pain sensations (137), cognitions and emotions influence behaviour such as return to normal activities and higher levels of stress are linked to poorer wound healing (88). Analysis of psychological preparation before surgery in a systematic review by Johnson in 1993 (166) showed that a benefit for negative affect, pain, analgesia use, length of hospital stay, behavioural recovery, physiological indices and patient satisfaction. Interest in improving recovery from surgery has continued since this review and more so with the attempt to optimize recovery programmes for maximum efficiency and positive patient experience. The economic benefits of shorter hospital stays and a quicker return to normal activity and return to work and also become important outcomes to study rather than immediate post-operative outcomes alone.

This systematic review took place once the rest of the studies were completed to inform us to the types of psychological interventions which can be used to improve them. It will then form part of a larger Cochrane Systematic Review on The effects of psychological preparation in all elective surgery. For this reason, I will follow the same methodology as submitted to Cochrane (167). This methodology has had input from all the authors of this review, however, I have carried out the gynaecology part of the review for this higher degree independently with supervision from the first author of the Cochrane Review (Dr

R Powell), who was also my MD supervisor. The methods section in this report has been derived from parts of the submitted Cochrane Protocol (167) appendix 18 with permission from the authors and under guidance from the first author Dr R Powell. This is to maintain consistency in this systematic review with the larger Cochrane review.

In the real life pragmatic situation, hospital statistics report that women who have undergone a vaginal hysterectomy, with no abdominal incisions, have an average post-operative stay of 3.2 days in England (6), which is longer than the laparoscopic approach and not much different to the stay after the abdominal route despite evidence for a shorter stay for vaginal and laparoscopic routes (48) . This may indicate that in strictly controlled experimental designs clinicians are potentially achieving optimum care efficiency through their beliefs about therapy and through the inadvertent psychological preparation of all patients. This could be in the form of stringent consent procedures with increased access to support mechanisms and follow up. It may be that patients' and health care professionals' beliefs and expectations of recovery play a more significant part in what actually occurs outside clinical trial settings. Aspects of this could be amenable to psychological intervention to improve recovery outcomes.

Psychological preparation incorporates a range of strategies designed to influence how a person feels, thinks or acts (emotions, cognitions or behaviours). The benefits of psychological preparation for surgery have been evaluated in a meta-analysis (166). It identified many different types of psychological preparation, including procedural information, sensation information, behavioural instruction, hypnotic and relaxation training, psychotherapeutic interventions and cognitive behavioural approaches. They

were found to be beneficial for a range of outcome variables such as negative affect, pain, and pain medication, length of hospital stay, behavioural recovery, clinical recovery, physiological indices and satisfaction.

Information giving

Patients give high importance to the information given to them by health care professionals over other sources. It influences behaviours such as when to return to normal activity and the degree of analgesia use (166). However, there is much variance in the beliefs and practices of health care professionals in the advice they give to patients (132). Information giving to patients pre-operatively can be categorised into sensory, procedural and behavioural. Sensory information describes the experience for example, what it will feel like and any other relevant sensations (e.g. taste, smell). Behavioural instruction consists of telling patients what they should do to facilitate either the procedure or their recovery from the procedure. For example, instructions about post-operative breathing exercises to help prevent respiratory infections. Procedural information describes the process that the patient will undergo i.e. what will happen, when it will happen and how it will happen. As a result patients should be more aware of what to expect which will result in reduced anxiety with reduced pain sensations (137).

Women undergoing elective gynaecology laparoscopy who were given procedural information about the surgery had significantly less analgesic requirements and reported a more rapid return to full health (132, 137). In addition, stress has been linked to the slower healing of wounds through psychoneuroimmunological mechanisms (138) and

reducing anxiety has been defined as one of the principles of conducting a pre-anaesthetic consultation (87). Although pre-operative information is available, consideration should be given to including those categories of information which improve recovery.

Relaxation

Relaxation techniques can be used before surgery to reduce tension and anxiety. These include progressive muscle relaxation (where each muscle group is tensed and then relaxed), simple relaxation (each muscle group is relaxed in turn), breathing techniques (e.g. practice of diaphragmatic breathing) and guided imagery (e.g. imagining a pleasant, relaxing environment). A mixture of relaxation training and sensory and procedural information giving was used as a pre-operative preparation for patients undergoing a cholecystectomy. The group who received this preparation reported less pain and higher levels of activity (87).

Cognitive therapy

Cognitive interventions aim to change how an individual thinks, especially about negative aspects of the procedure. Information seeking is more common in people who have an internal locus of control. The locus of control is a psychological term referring to the extent to which individuals believe they control events that affect them. People can have a perceived internal or external locus of control. People with external locus of control will believe strongly in other people, fate and in their destiny, whereas someone with a strong internal locus of control will believe that they have the ability to influence their own future. Those with an internal locus of control benefit from knowing more

information and are able to reduce their anxiety levels about forthcoming surgery, whereas the same information may increase the anxiety levels of someone with an external locus of control as they may rather not know the details (168). A randomised trial of procedural information, cognitive coping techniques and general ward information given to patients who had a hysterectomy showed that cognitive coping had the most effect on recovery (140).

Hypnosis

Hypnosis can be defined as when ‘one person (the subject) is guided by another (the hypnotist) to respond to suggestions for changes in subjective experience, alterations in perception, sensation, emotion, thought or behaviour’ (144). Hypnosis may be seen to act either as a cognitive or a relaxation intervention. There is now evidence from a meta-analytical review that hypnosis positively affects immune function and may work through psychoneuroimmunological mechanisms (138).

Emotion-focussed Intervention

Emotion-focussed intervention aims to reduce the negative emotions that are predictive of negative post-surgical outcome. The patient’s coping tendency has also been studied in relation to the information patients need. People can cope with situations through mainly problem focused strategies or emotion focused strategies. Those who use problem focused strategies make plans to improve the situation and feel better when these are followed through. Emotion focused individuals tend to alter their own cognitive

interpretation of the situation rather than change it, for example, ‘looking at the bright side’ (145).

Objectives

To explore the effects of psychological preparation on recovery outcomes after a hysterectomy. This systematic review will update the previous meta-analysis (167) and focus on hysterectomy.

Search Methods

The search included the Cochrane Central Register of Controlled Trials

(cantra) (*The Cochrane Library*, latest Issue); Medline

(Ovid SP) (1950 to date); Embase (Ovid SP) (1982 to date);

PsycINFO (Ovid SP) (1982 to date); Cinhal (EBSCOhost)

(1980 to date) and Amed (Ovid SP) (1982 to date). The literature search was performed by MS. The following free text keywords were used:

Search Terms

Hysterectomy

Each psychological preparation term ('psychological preparat*', education, information, instruction, cognitive interven*, 'cognitive behavior?ral therapy', 'cognitive therapy', 'behavior*ral therapy', hypnosis, relaxation, guided imagery) AND 1

ALL psychological preparations (link with OR) AND 1

Recovery

4 AND 3

No limitations were applied for year of publication, study design or language and translations were obtained for articles not in English. The reference lists and citations of included papers were also searched for additional sources. The literature search was completed in 2010. A total of x citations were obtained (figure 1). The full text articles were assessed for eligibility by their abstracts. Full text was sourced if the abstract was for a randomized controlled trial.

Methods

Selection criteria

Any randomised controlled trial that:

1. uses random or quasi-random allocation and appropriate follow up;
2. compares the positions listed under objectives.

Types of participants

Women undergoing any gynaecological surgical procedure under a general anaesthetic.

Types of Intervention

Outcome measures

Primary outcome measures

1. Postoperative pain

1a. Postoperative pain intensity using the following hierarchy:

- i) the pre-specified pain outcome (if given);
- ii) a visual analogue scale, from 0 to 100 (or 0 to 10);
- iii) McGill Pain Questionnaire (MPQ) intensity rating, Present Pain Intensity;
- iv) other MPQ ratings i) Pain Rating Index (weighted or unweighted),

ii) Number of Words Counted;

v) other pain intensity scale.

Secondary Outcome measures

1. Negative affect: post intervention and postoperative

2. Resource use

a. Length of stay, in hospital, in post anaesthesia care unit.

b. Postsurgical analgesia use: proportion of patients requiring an

unplanned analgesia intervention in the post anaesthesia care unit,

within 24 hours, at any time in hospital, after discharge.

3. Behavioural recovery (defined as: resumption of performance of tasks and activities).

Data collection and analysis

Data was collected straight onto Review Manager 5.1. We considered the population, intervention details and their timing, number of intervention groups, the control group intervention, adherence to intervention, attrition rate and loss to follow up. For each study and intervention, we collected data on the study's primary and secondary recovery outcome measures. Quality of studies was assessed using the CONSORT tool looking for data collection, patient enrolment and randomization techniques, sample definition,

baseline matching of groups, blinding, outcome assessment, follow up and a priori power calculations.

Each article was assessed by two assessors (MS and MD, a research fellow on Prof JKG team 2009) and any uncertainty was resolved by discussion with JKG. Analysis was done using Review Manager 5.1 using a confidence interval (CI) of 95% and significance P value of below 0.05. Forest plots were used to show pooled effects.

Measures of treatment effect

Dichotomous data

For dichotomous data, we present results as summary risk ratio with 95% confidence intervals.

Continuous data

For continuous data, we used the mean difference if outcomes are measured in the same way between trials. We used the standardised mean difference to combine trials that measure the same outcome, but using different methods.

Unit of analysis issues

Dealing with missing data

For included studies, levels of attrition were noted. The impact of including studies with high levels of missing data in the overall assessment of treatment effect were explored using sensitivity analysis.

For all outcomes analyses were carried out, as far as possible, on an intention-to-treat basis, i.e. we attempted to include all participants randomised to each group in the analyses. The denominator for each outcome in each trial was the number randomised minus any participants whose outcomes are known to be missing.

Assessment of heterogeneity

We used the Chi² statistic to measure heterogeneity among the trials in each analysis. We regarded the level of heterogeneity as substantial if it was above 50%.

Data synthesis

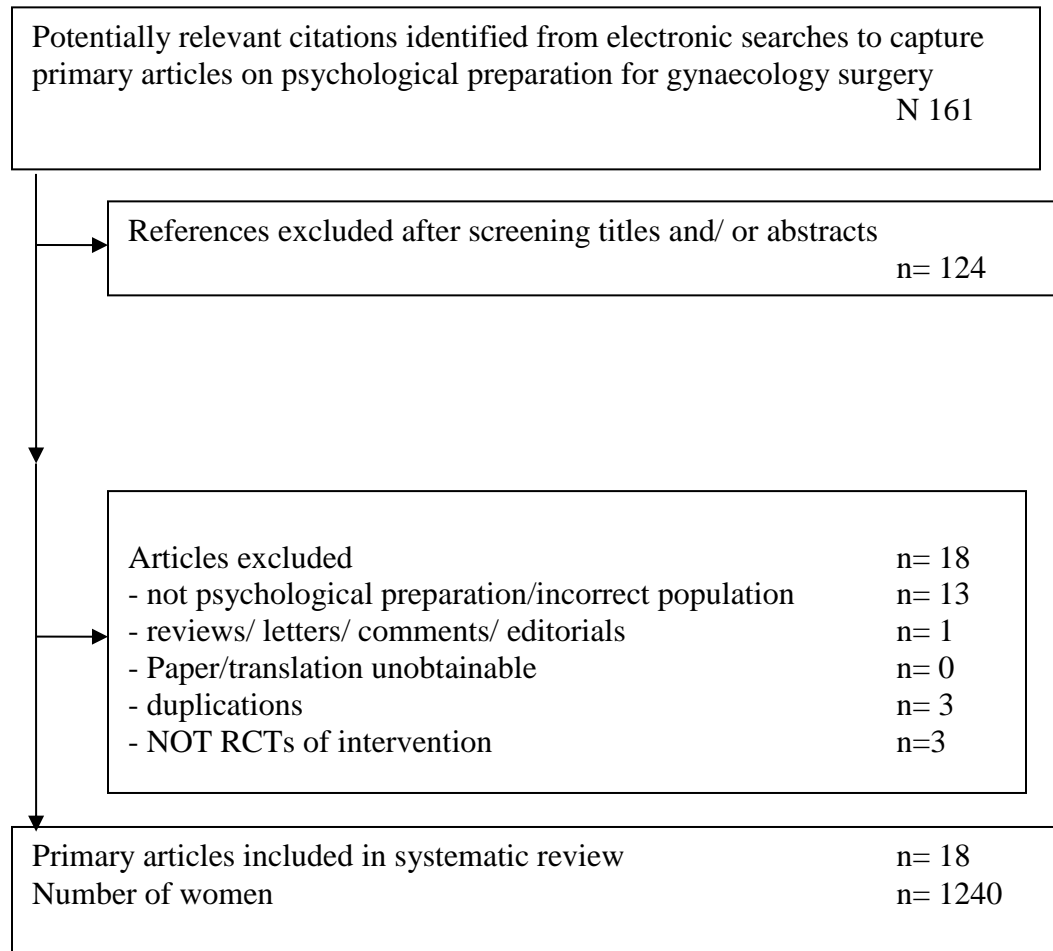
We carried out statistical analysis using the Review Manager software ([RevMan 2008](#)). We used fixed-effect inverse variance meta-analysis for combining data where trials were examining the same intervention, and the trials' populations and methods were judged sufficiently similar. Where we suspected clinical or methodological heterogeneity between studies sufficient to suggest that treatment effects may have differed between trials we used random-effects meta-analysis.

Publication bias

Publication bias was considered as per the Cochrane Handbook section 8.4.5. This is the systematic difference between reported and non-reported findings. Those studies which show a significant difference between the intervention and control are more likely to have been published than non-significant findings. The Cochrane handbook refers to this type as bias as substantial.

Results of search

Figure 7.1 Process from initial search to final inclusion for psychological preparation in gynaecology surgery.



Description of studies

A total of 21 abstracts were eligible. One paper was written in Chinese and translated by TT. After reviewing the potential papers, 3 were not included in the review as they were not randomized trials of psychological preparation (Melzack 1996, Mogan 1985, Moon 1984). The remaining 18 papers were included in the review. All included studies compared psychological preparations in a randomized controlled trial. Recovery outcomes were assessed in all trials.

Included studies

There were 18 studies included in this review (Table 7.1). Two of these studies had more than one psychological preparation method and so were analysed as separate studies (Laurion GI 2003 and Laurion MU 2003, Nilsson 2001 M&T and Nilsson 2001 Music). A total of 1240 women were included in the studies.

Table 7.1 Characteristics of included studies

Study	Participants	Intervention	Description of intervention	Outcomes
Andrzejowski 1996	36 patients ASA grade I or II for TAH	Acupressure and acupuncture	At the pericardium 6 point on both wrists	Post-operative nausea and vomiting
Block 1991	109 intervention group, 100 control. Operations on the fallopian tubes, total abdominal hysterectomy, vertical banding gastroplasty, cholecystectomy, and ovarian cystectomy or myomectomy from University of Iowa Hospital and Clinics	Therapeutic positive suggestions tape	6 minutes female voice at a deliberate rate of speech. Positive suggestions about recovery.	Length of stay, opioid use, pain, urine, flatus, bowel function and STAI
Cheung 2003	48 in intervention and 48 in control. Chinese women who spoke Cantonese who were having an elective abdominal hysterectomy	Information booklet with cognitive intervention	Cognitive distraction and reappraisal (Lazarus 1984)	Post-operative anxiety, pain, analgesia use, patient satisfaction.
Dudley 2002	42 women having hysterectomy in a private clinic in Virginia. 19 had massage, 22 controls.	Massage therapy	30 minutes Swedish massage from a female therapist	Length of stay, analgesia use
Evans 1998	Total abdominal hysterectomy patients at St Thomas' Hospital London. 19 in intervention group, 20 controls.	Positive suggestion tape	Positive suggestions under general anaesthetic	Pain, nausea, defecation and flatulence, length of stay, mobilisation
Heye 2002	70 elective hysterectomy patients 35 in each arm	Foster pain intervention	24 minute videotape of a nurse showing breathing and movement skills with four post-operative mobility activities to improve self-efficacy.	Pain
Laourion GI 2003	Convenience sample of 84 women having gynaecology laparoscopic surgery	Guided imagery	Listened to Health Journeys for People Undergoing Surgery by Naparstek under general anaesthesia	Post-operative nausea and vomiting and pain
Laurion MU	Convenience sample of	Audiotape of		Post-

2003	84 women having gynaecology laparoscopic surgery	piano music	Listened to piano music with earphones under general anaesthetic	operative nausea and vomiting and pain
Lobb 1984	30 women Women in Cleburne Texas fall of 1981 and winter 1982 undergoing hysterectomy	Relaxation training and desensitization	Pre and postoperative. Desensitization for surgical trauma included post-operative stimuli	Length of post-operative hospital stay
Maroof 1997	50 elective hysterectomy patients	Positive intra-operative suggestion tape	Male voice speaking in the patient's dialect 15 minutes via headphones under GA suggesting they would experience no sickness.	Emetic episodes
Nilsson 2001 M&T	90 women ASA I-II elective hysterectomy	Music with therapeutic suggestions	Music - Relaxing and calming music with sea waves. Therapeutic suggestions-Relaxing and encouraging suggestions in a male voice by a person with extensive experience in hypnotherapy	Pain, post-operative nausea and vomiting, bowel function, fatigue, length of stay, well-being
Nilsson 2001 Music	90 women ASA I-II elective hysterectomy	Music alone	Music - Relaxing and calming music with sea waves.	Pain, post-operative nausea vomiting, bowel function, fatigue, length of stay, well-being
Oetker- Black 2003	108 hysterectomy patients Midwest Teaching Hospital	Self-efficacy enhancing teaching programme	Pre-operative instruction on mobility, turning, deep breathing, pain reduction through relaxation.	Pain on VAS, SAI, ambulation, day 1, length of stay
Study	Participants	Intervention	Description of intervention	Outcomes
Perri 1979	26 women for elective vaginal hysterectomy	Progressive muscle relaxation	Two 90 minute individual sessions pre-operatively (Bernstein and Borkovec)	Pain
Poolsawal 2003	90 patients for TAH for cancer Bangkok University Hospital	Relaxation training	Benson's Respiratory One Method Technique	Anxiety by HADS

	19/11/1999-29/02/2000			
Ridgeway 1982	60 St Georges Hospital London women admitted for elective hysterectomy (10 in each group)	Information about surgery, Cognitive coping technique	Information - procedural and sensations Cognitive coping - Positive control of how to view events	Pain, waking frequency, nausea, analgesia use, mood scale
Taylor 1998	62 patients having elective abdominal hysterectomy	Music	Music of their choice on headphones played in last 30 minutes of surgery and first hour post op vs headphones alone.	VAS pain score, Graphic pain intensity score
Vitale 2006	22 Elective hysterectomy (10 in experimental group)	Reiki	3 Reiki Nursing Interventions 30 minutes each at timed intervals at day 1, 24hours and 48 hours post-operation. Standard Reiki hand positions, implemented for hand placement consistency and each hand placement was for 3 minutes. Reiki by expert Reiki Practitioners minimum level III, supervised by master Reiki registered nurse.	

Data analyses results

A total of 1240 women were included in all studies. There were 9 studies which assessed the effect of psychological preparations on pain using a visual analogue score (VAS) and they did not find a statistically significant effect 0.78 (1.04, -0.52 figure 7.2). Analgesia requirements by morphine dose was assessed in 6 studies. It did not find a significant pooled effect for the psychological interventions -3.31 (-5.41, -1.22 figure 7.3). Nilsson 2001 compared time to walking, wellbeing at day 1 and fatigue for patients who listened to music alone and those who listened to music with therapeutic solution as compared to no intervention and did not find any statistically significant difference -0.20 (-5.85, 5.46 figure 7.4), -0.55 (-1.01, -0.09 figure 7.5) and 0.41 (-0.78, -0.04 figure 7.6) respectively. Anxiety as measured by the State Anxiety Questionnaire (STAI) was assessed in two studies; Vitale 2006 and Block 1991 (figure 7.7). This showed a significant difference for trait anxiety which was higher in patients who had not had the psychological intervention [$P < 0.00001$, mean difference 7.78 (7.19, 10.61)]. Post-operative nausea and vomiting was studied in 4 studies. Again, no statistically significant difference was found in the pooled effect -0.06 (-0.49, 0.38 figure 7.7). Length of hospital stay post operation was assessed in 4 studies. (figure 7.8). Of all the psychological preparation techniques, positive suggestion under a general anaesthesia in the Evans 1988 paper was the only one which had a statistically significant effect. It reduced length of post-operative hospital stay -31.00 (-48.35, -13.65), however, this is an older paper and the mean length of stay was much longer than the newer studies. Pooled length of stay for the 4 studies was reduced in the group who had any psychological intervention [$P 0.03$, 5.65 (-10.82 to -0.48)].

Risk of bias

Figure 7.10 shows the risk of bias as assessed by the criteria of random sequence generation, allocation concealment, blinding of participants and researchers, blinding of outcome, incomplete outcome data and selective reporting. Red indicates high risk of bias and green indicates low risk. Yellow is where the risk was unclear although there was reference to the risk, in some instances, there was no mention of the risk being assessed so these were left blank. On the whole, there was mainly high or unclear risk of bias

Figure 7.2

Pain at 24 hours measured by visual analogue scale

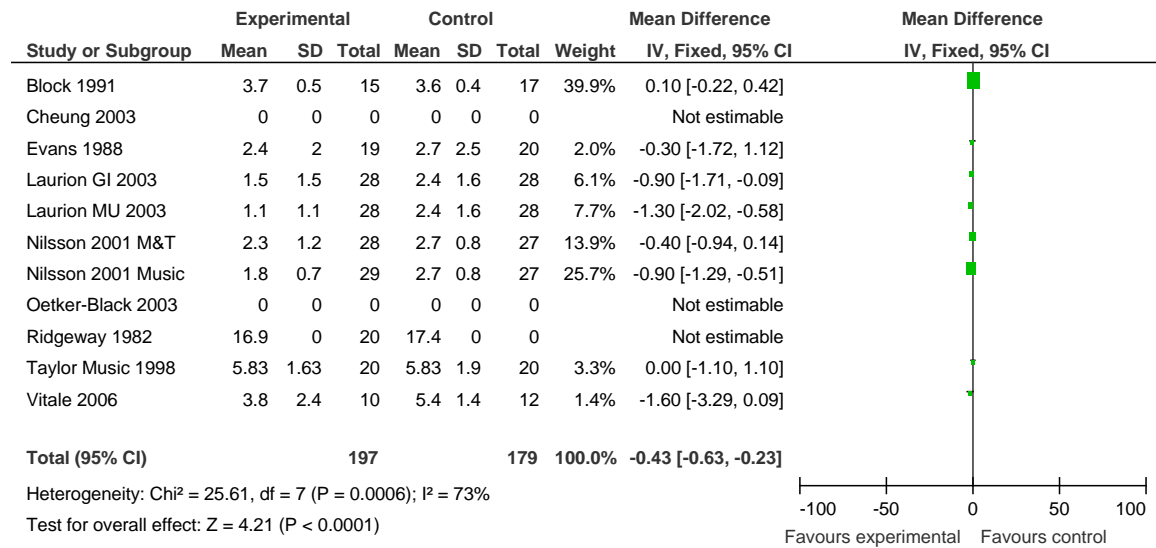


Figure 7.3

Pain measured by morphine use in mg

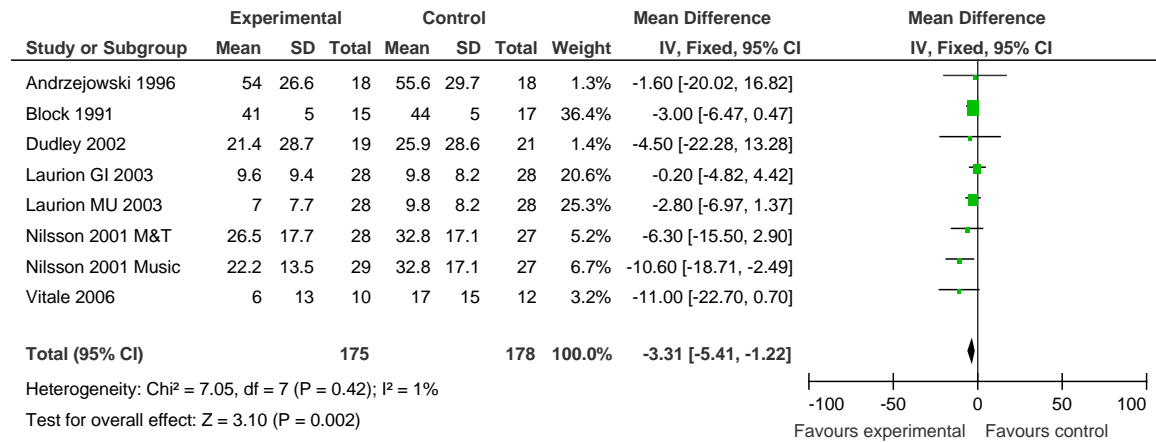


Figure 7.4

Behavioural recovery: time to walking

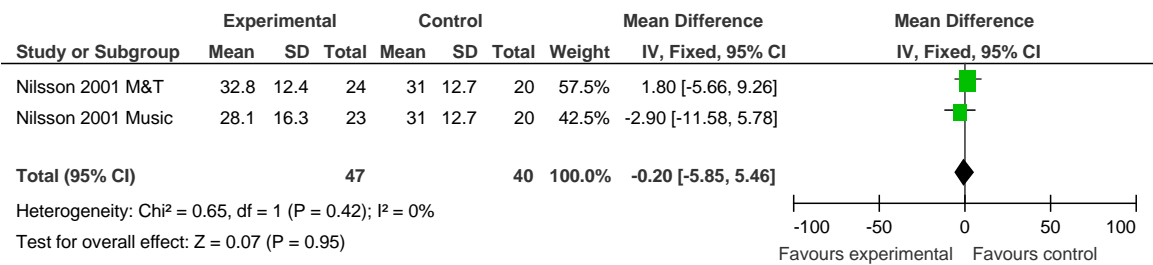


Figure 7.5

Behavioural recovery: wellbeing day 1 post surgery

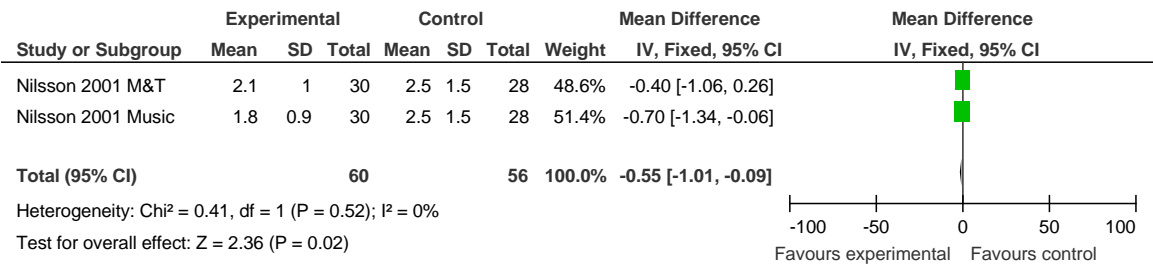


Figure 7.6

Behavioural recovery: fatigue day 1

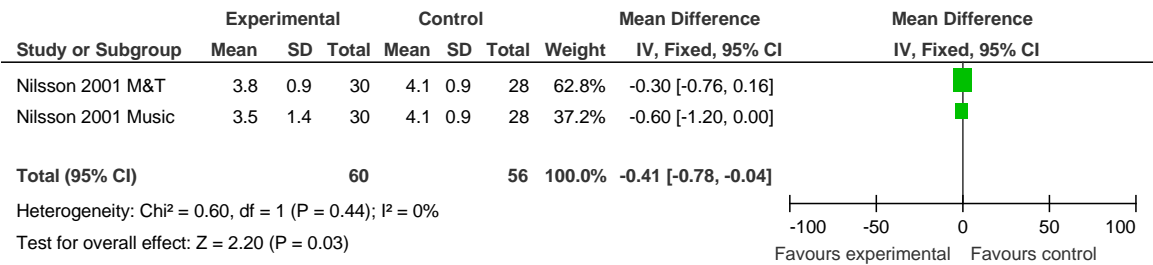


Figure 7.7

Negative affect: STAI Trait questionnaire

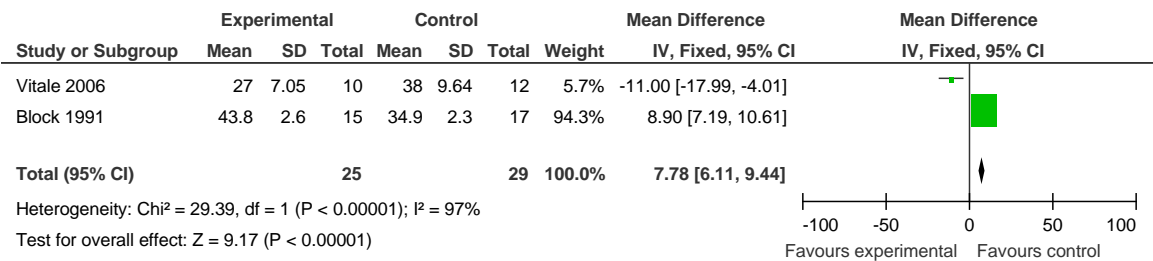


Figure 7.8

Negative affect: nausea and vomiting day 1

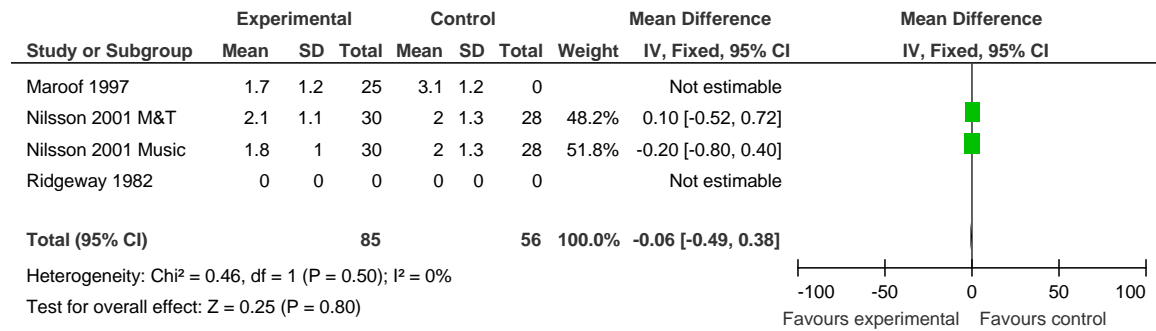


Figure 7.9

Length of stay

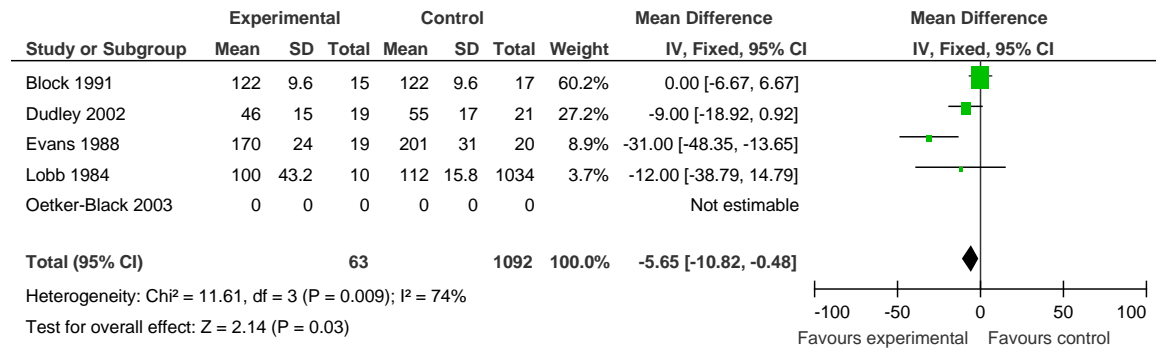


Figure 7.10
Risk of bias summary for
included studies

	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessment (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
Andrzejewski 1996	+	?	+		+	+	+
Block 1991	+	+	+	+	+	+	+
Cheung 2003	+	+	+	+			
Dudley 2002	+	+	+	+			
Evans 1988	+	+	+	+			
Heye 2002							
Laurion GI 2003	?	?	+		+	+	+
Laurion MU 2003	?	?	+	?	+	+	+
Lobb 1984							
Maroof 1997	?						
Nilsson 2001 M&T							
Nilsson 2001 Music	+	+	+	?	+	+	+
Oetker-Black 2003	+	+	+	+			
Perri 1979							
Poolsawal 2003	+	?	+	?	+	+	+
Ridgeway 1982	?	?					
Taylor Music 1998	+	+	+		+	+	+
Vitale 2006	+	+	+	+			

Figure 7.11 Funnel plot Pain

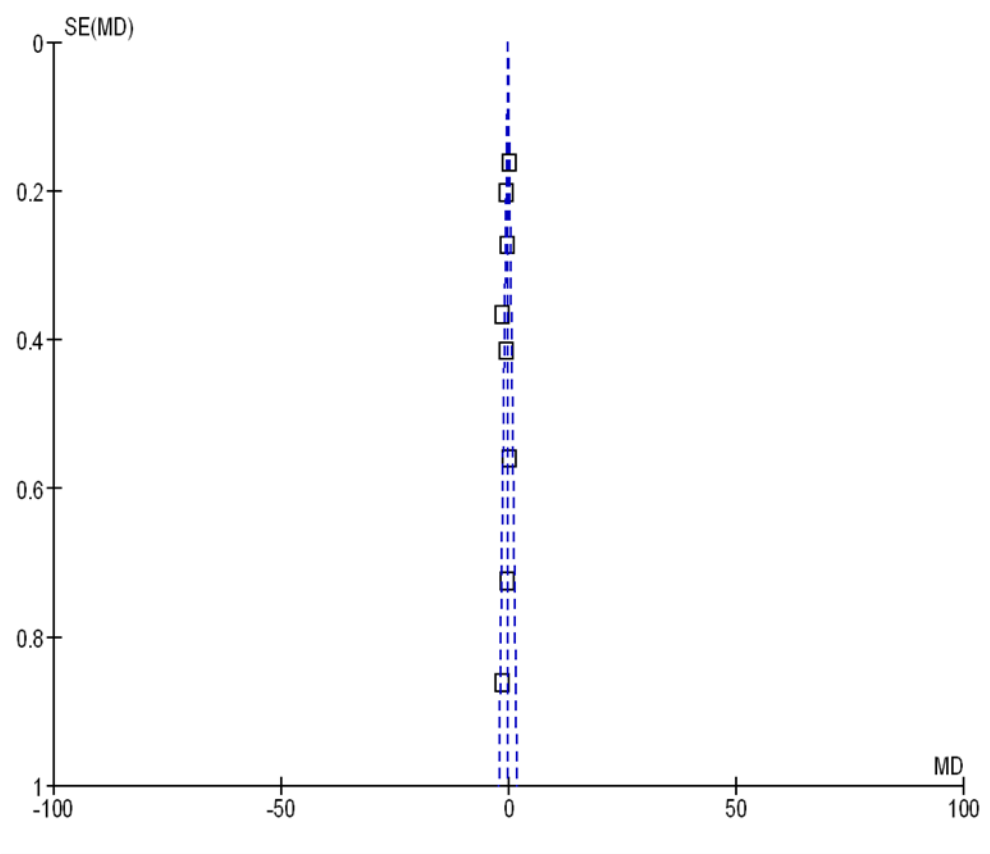


Figure 7.12

Funnel plot morphine use in mg

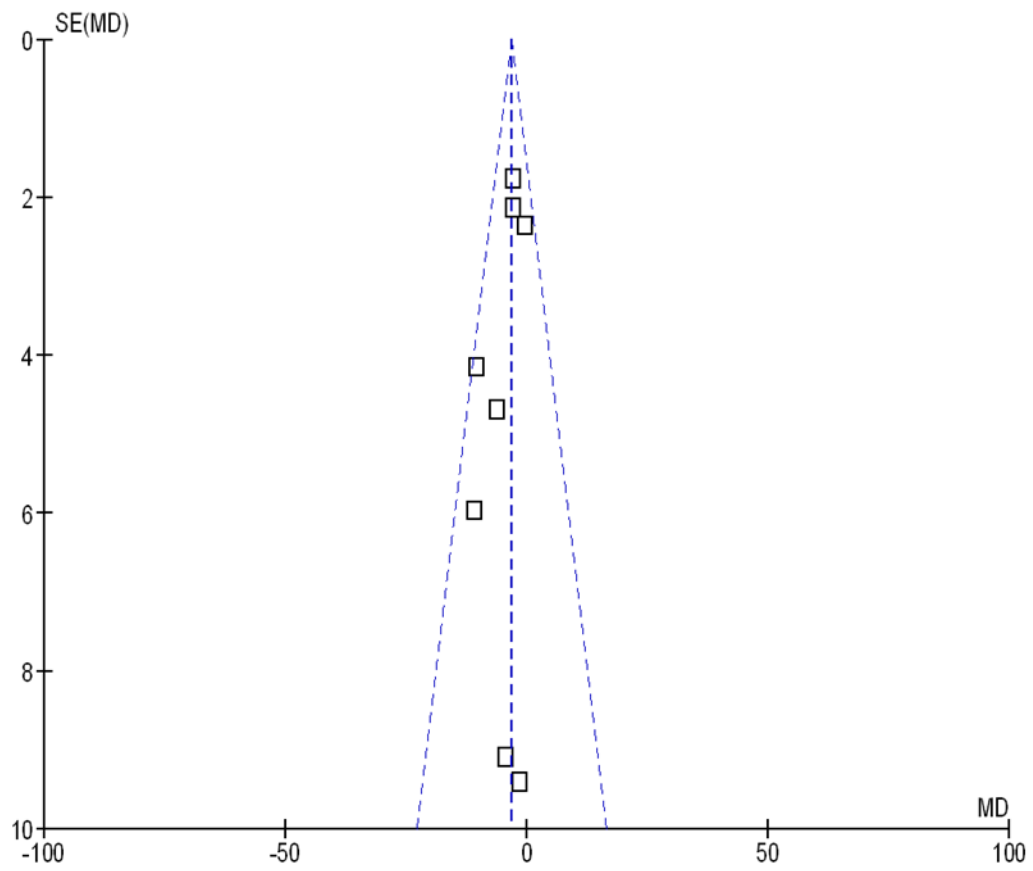


Figure 7.13

Funnel plot Time to walking

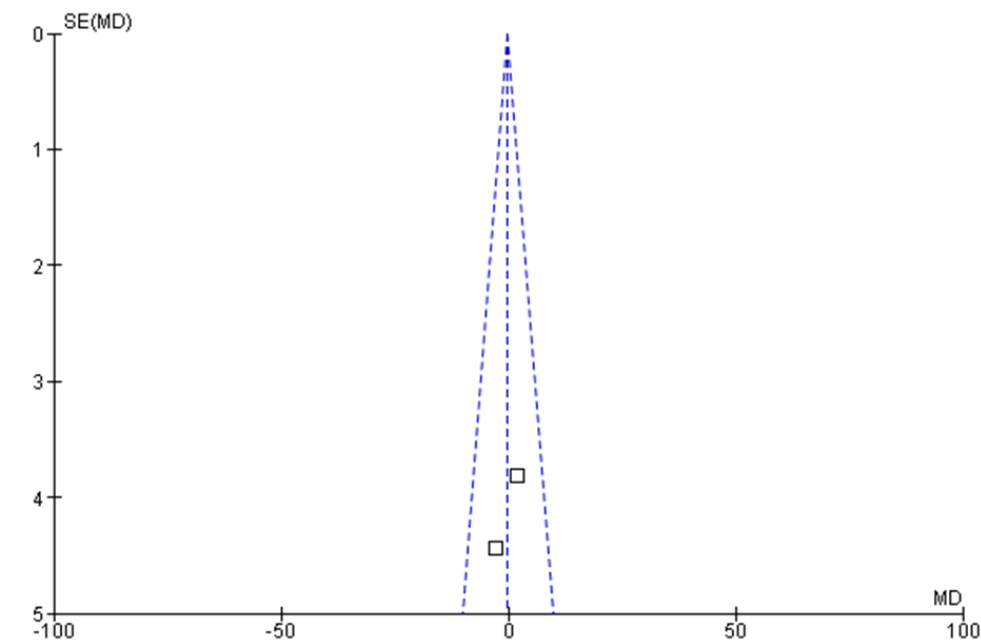


Figure 1.14

Funnel plot Wellbeing day 1

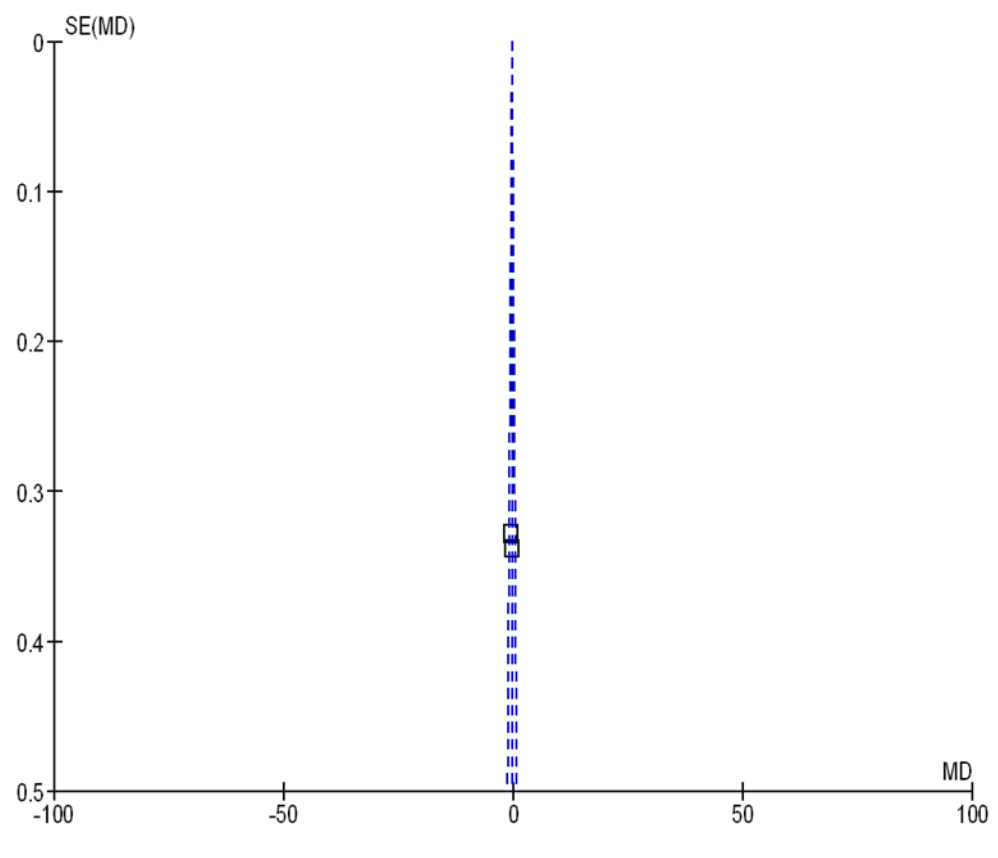


Figure 7.15

Funnel plot nausea and vomiting day 1

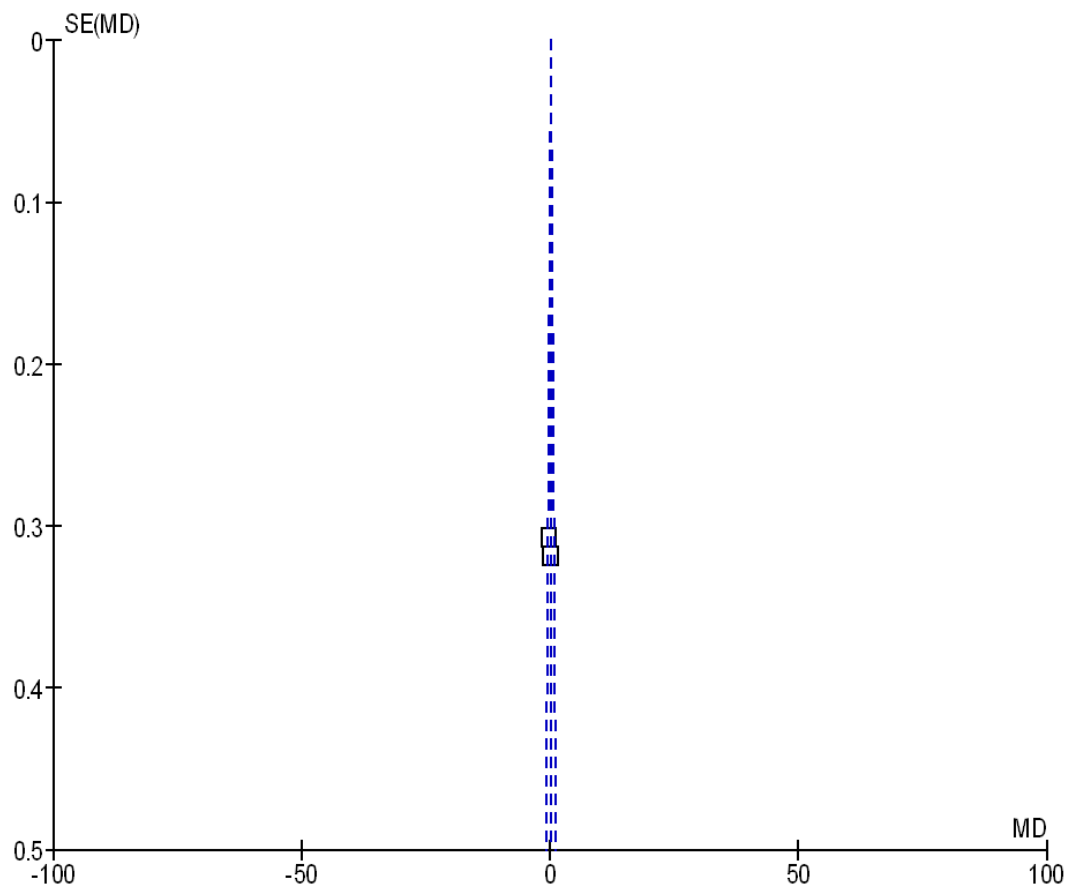


Figure 7.16

Funnel plot Fatigue day 1

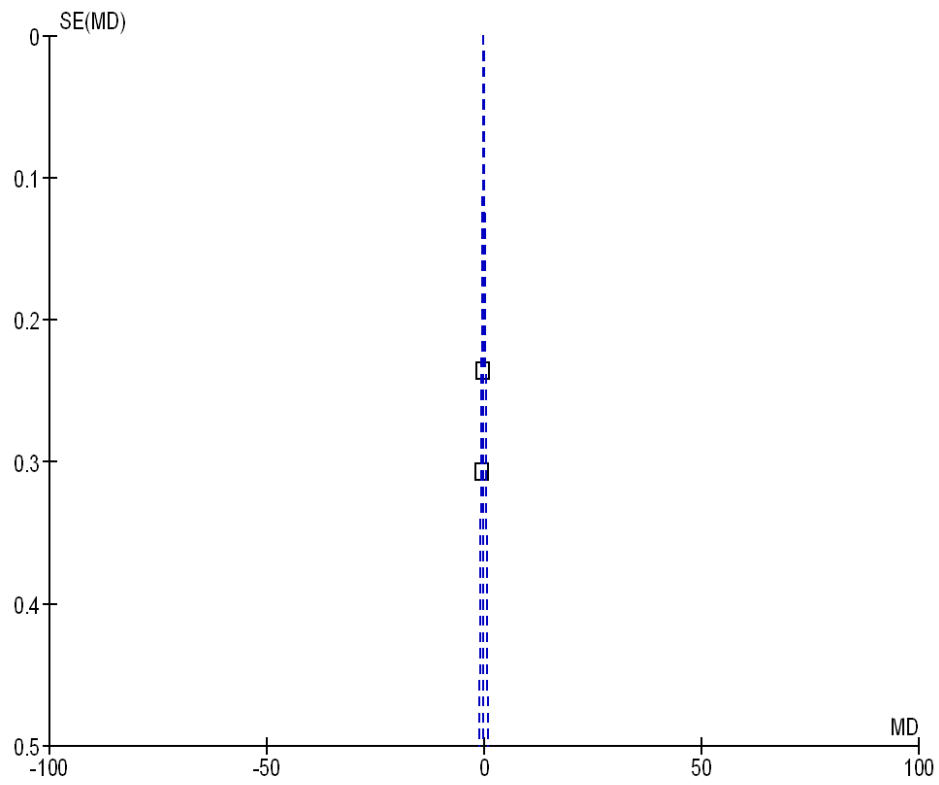


Figure 17
Funnel plot STAI Trait

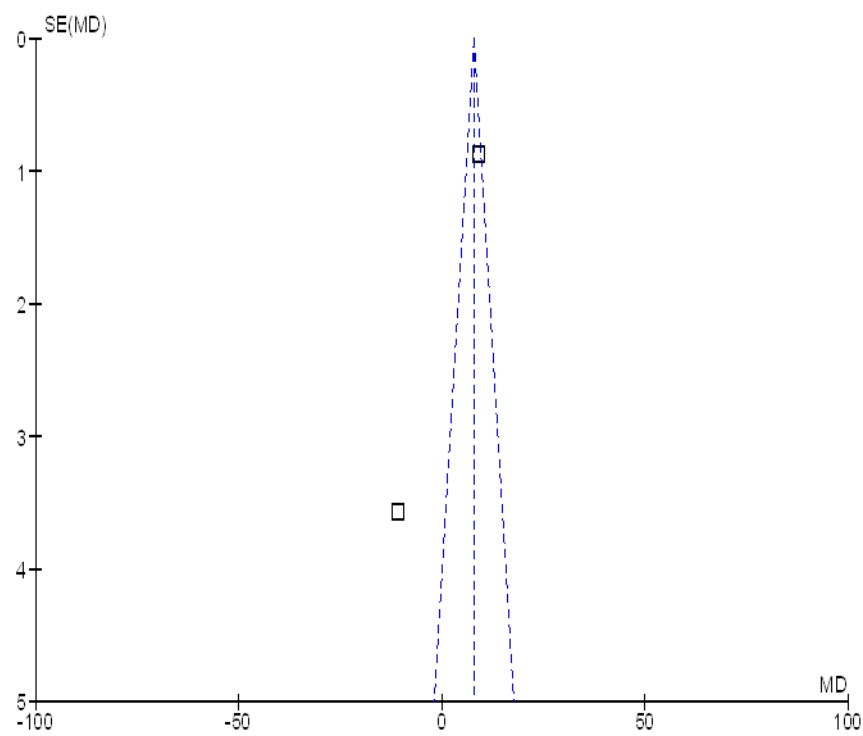
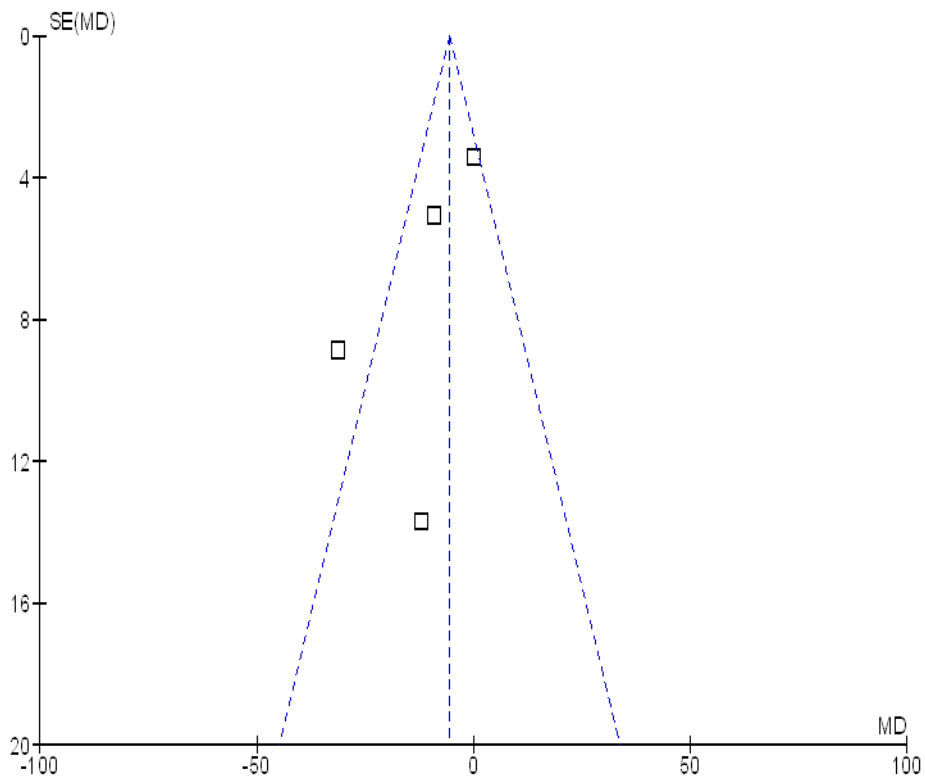


Figure 7.18

Funnel plot length of stay



Discussion

The concept of psychological interventions to improve recovery from hysterectomy was debated as far back as 1982 when Valerie Ridgway published her research on cognitive coping and suggested that this was an explanation for the variation in recovery after surgery (91). In our review however, there was much heterogeneity among studies in their definition and type of the interventions which makes the comparisons challenging, however we did see that psychological interventions could reduce the length of stay after surgery, particularly suggestion under general anaesthesia as well as trait anxiety. We rated the quality of most of the evidence for outcomes as ‘low’ and due to the unclear or high risk of bias of reporting. This is similar to other reviews of psychological preparation for surgery (169, 170). Although we know that psychological states affect recovery from surgery (105, 171) and that interventions focussed at these could improve recovery, we need more robust trials to be able to answer the question of which interventions are effective. Furthermore, there is a variety of recovery outcomes which were not always presented using robust measures which could be compared in the analysis and what a favourable outcome might be to clinicians and patients. This review was undertaken as part of early work towards a larger review, where the authors came to similar conclusions about psychological interventions from all surgery involving a general anaesthetic (172). Recovery has many components including measurable clinical aspects such as vital observations, normalising of test parameters, the use of analgesia, return of physiological function such as passing urine or opening their bowels, number of days as an inpatient and mobility. From the perspective of the patient, a favourable outcome may be more related to important aspects of their lives such as being able to

sleep normally, looking after their families, socialising, feeling emotionally back to normal or being able to go back to work. There is evidence where psychological interventions have been shown to improve health and recovery such as from ischaemic heart disease (173) where a systematic review of intensive relaxation therapy improved physical recovery such as resting heart rate and exercise tolerance. Psychological interventions are used as established therapy in many areas of health and wellbeing such as with psychotherapy and behavioural medicine where they have been shown to be cost effective (174). It is likely therefore that there is some merit in psychological interventions to enhance recovery outcomes.

Conclusion

From this review, psychological interventions such as suggestion under general anaesthetic could reduce length of stay; and could reduce trait anxiety. Due to the variation between interventions however, higher quality evidence is needed in order to answer the question of which psychological interventions work and which recovery outcomes are best affected.

Chapter 8: Discussion

Overview of findings

We were not able to find any difference in the time women returned to work according to their employment status or incapacity benefit type. From this study, we have found that there is a great deal of variation in the beliefs of UK gynaecologists regarding recovery from laparoscopic, vaginal and abdominal hysterectomy, particularly in longer term return to normal activities once discharged from hospital. The difference was not explained by geography; however there was some explanation by experience and grade of specialist. This is likely due to the building of personal experience with patients. Moreover, this variation of advice was seen in the gynaecology nursing staff at Birmingham Women's Hospital. Health care professionals reported that their advice was based on personal beliefs rather than on national or local evidence based guidelines such as NICE. This study on variation in the beliefs of healthcare professionals highlights the importance of understanding actual recovery experiences of women who have undergone hysterectomies from each of the surgical routes.

My study of the experiences of women who have had a hysterectomy highlighted that regardless of route of surgery, the expectations and fears of women were similar before surgery such as difficulties making sense of the large amounts of information available, the influence of friends and family who have previously had this surgery as well as their own experiences of previous surgery. It is important to remember that women who have a hysterectomy are likely to have responsibility of dependent children, and the cohort in this study talked about the concerns they had around childcare and the practical

arrangements they had made. Women had tried to improve their health in order to enhance their recovery and one woman talked about taking time off work and potentially losing her job. Fears before surgery included the effect on emotions, although some women felt that the hysterectomy would be a positive influence on their emotions. This part of the study confirmed how women required guidance from health care professionals about when to resume activities such as sexual intercourse. Women talked about a variety of ways to prepare for their recovery and some set goals before surgery. The surgical route of hysterectomy appeared to be governed by their surgeons and the need to gain further advice on whether to have their ovaries removed or not. Before surgery, there was confusion with conflicting advice about length of stay, again correlating with the health care professionals' variation in beliefs. Women talked about listening to their own bodies and interpreted pain as a marker to stop the activity associated with this feeling. Addressing expectations and concerns before surgery is important as this study has demonstrated that anxiety levels are increased.

After surgery, there were specific concerns in the group who had had a vaginal hysterectomy around pain in sitting and opening their bowels, which is expected due the fact that the incision is in the vagina close to the rectum and perineum.

The laparoscopic hysterectomy group did experience a lower length of stay; however, the actual recovery milestones were more associated with the individual rather than the surgical route in general. Women who had an abdominal hysterectomy had higher anxiety scores and lower quality of life scores at 3 months than the laparoscopic and vaginal group. The vaginal hysterectomy group reported the highest quality of life scores after surgery. Most participants did not drive until after 6 weeks, and in general the

recovery experience was better than women had expected, particularly in relation to sexual recovery and effect on their quality of life, again regardless of route of surgery.

This study concurred with the published literature on the strong influence of healthcare professionals in the recovery period.

When considering what psychological interventions may be useful to enhance recovery from hysterectomy, this systematic review concluded that there was variation in interventions, making comparisons as a whole a challenge, as well as using differing outcome measures. It may be more useful to compare similar interventions such as music therapy or relaxation therapy on the same outcome.

Impact for future studies and practice

This study adds to the understanding of recovery from hysterectomy. In particular, it highlights the variation in advice women receive from their health care professionals, and the gap in evidence based guidance for recovery outcomes.

It raises the question of developing guidelines for both healthcare professionals and patients to help with realistic expectations of recovery from hysterectomy and what may alter it. Furthermore, it shows that despite research showing that recovery is faster from less invasive surgical approaches, the beliefs and behaviours of both patients and healthcare professionals do not reflect this. Guidance would support confidence in enhanced recovery particularly for laparoscopic and vaginal hysterectomy routes.

This study highlights the importance of influencing healthcare using a more holistic bio psychosocial model, paying attention to the ideas, expectations and concerns of women who have a hysterectomy in order to enhance their recovery and reduce levels of anxiety. More patient focussed ways of providing information, addressing concerns and building confidence are required which address multiple aspects of recovery should be developed and tested in trials, such as using electronic media, online patient and family resources such as videos accessible whenever the patient requires them, virtual support networks and virtual consulting with health care professionals. This will help us to both understand and support longer term recovery better once the patient has been discharged from the hospital.

With limited NHS resources, it is important to empower patients with the tools they require to aid their own recovery. Further qualitative studies will help us to understand which recovery outcomes are valued most by women recovering from hysterectomy and how we can work to improve these outcomes.

Reflective critical analysis and learning points

It has taken 8 years to complete this MD which has posed a number of problems, particularly at the write up stage. The study itself was completed within 2 years while I was in a clinical lecturer post; however the analysis and write up was delayed. This was due to a number of factors which were disclosed to the University including being appointed to my first consultant post; for which I requested a one year break in order to focus on my new role. Subsequently, I experienced a number of major personal issues which were life changing and I took a break from the MD in order to focus on my

personal life. It has taken 3 years to get back into a position to find balance to come back to my MD. Once I did come back to my MD, I found that I had to re-learn the data and re-familiarise myself with the literature as well as those chapters I had already written. Furthermore in this time one of my supervisors moved jobs to Manchester, this made supervision with her challenging as I was not able to meet with her. My primary supervisor advised me to continue with him. Once I re-organised my work, I found that I needed to update my literature search. Unfortunately, in the time which had passed. Even though my search was saved online, the National Electronic Library for Health database had been wiped and all saved searches were lost. Therefore, I had to re-run the search again using the saved search terms in 2015. By this time, my librarian advised me to run the search on the individual databases rather than the collection National library due to some unreliability in the system. Once the search was completed, again I had to start the process of collecting new abstracts, reviewing the literature for new publications and applying it to my work, in some cases, having to re-write chapters as a result. Upon reflection, this process was like starting my MD over again and I had not appreciated the amount of work and time it would take. With time, the literature around enhanced recovery had moved on, particularly in gynaecology oncology. Although there were cohort studies of total abdominal hysterectomy showing reduced length of stay without an increase in readmission rates or post-operative complications (11), (175), (176). In 2016, Lena Wijk (11) suggested that outcomes from gynaecology oncology could be extrapolated to benign gynaecology recovery. Further studies of enhanced recovery in gynaecology have focused on ovarian cancer such as early re-feeding to improve bowel function and nutritional status with ERAS guidelines published for gynaecology

oncology (12). In benign gynaecology, there have been published studies showing reduced length of stay, increased cost effectiveness and decreased nursing time in prolapse and vaginal hysterectomy surgery with ER protocols (177, 178). Future studies in ER are now looking at protein loading rather than carbohydrate loading to reduce length of stay and infection rates after colorectal surgery (179). Once I had updated myself on the literature, was able to continue with analysing my data. Unfortunately, I found that I had missing data on the returned postal quality of life questionnaires, and there was no plan applied for as part of my ethics application to contact participants for this. The missing data was significant in some questionnaires and in particular, for the Menorrhagia Outcomes Disease Specific Questionnaire. Due to the fact that there was over 10% missing data, the analysis was not reliable according to the instructing handbook. In order to learn the statistical methodology of analysing the questionnaire, in particular how to deal with Z and T scores, I decided to run the analysis but to disregard the results. I am pleased that I persevered with this approach as I now have a greater understanding of this statistical methodology which I can use in future analyses and to understand research which has used these methods. From analysis of my qualitative data, particularly the quality of life questionnaires, I have learnt that it is important to check data during the study and to check and run the analyses as you go along to pick up any data problems early. If I had done this while I was running the study, I could have applied for an amendment to the ethics application to obtain the missing data. I feel that this was a missed opportunity which has greatly affected the quality of my study. As a result, any evaluation programme or audit I have lead since, I have designed it to capture data

electronically from the outset with mechanisms to alert me to incomplete data or analysis problems.

Reading and analysing the qualitative interviews also took much longer than I had anticipated. In order to really understand the interviews, it was important to read them multiple times and then think about what the participants had talked about, before being able to code them into themes. I have realised that the main part of the work for a qualitative study is in fact in the analysis of the interviews. This was different to other research I had been involved in where the collection of data or running of the trial or experiments took most of the time. In the future, I would plan my time differently and start to familiarise myself and start to analyse the interviews at the same time as conducting them in order understand them better, and to keep the link with the rest of the study. When I have come across qualitative studies since, I have found people using a concurrent analysis approach to direct future interviews. On reflection, I also think that I conducted too many interviews so I was left with a huge amount of data. It would have been a better idea to either run focus groups with the 3 routes of hysterectomy participants or to select a sample of 2 or 3 women in each hysterectomy route to speak to at the different time points. The multiple time points was interesting to track and understand the evolution of recovery, however again, it left me with a great deal of data. It may have been more useful to choose a time point after surgery to interview and use quality of life questionnaires at the other time points alone.

If I were planning this study again, I would think more carefully at the quality of life questionnaires I used. There are other more relevant questionnaires that I may have chosen such as the Hospital and Anxiety Depression Score instead of the STAI. More of

the literature I came across had used the HADS score, so it would have been more useful to compare my findings with other published studies. Thinking from the participant perspective and in order to understand why there was missing data, I think that there were too many questionnaires. The EQ5 was easier to complete and gave a good impression of overall quality of life. I feel that the SF12 and Menorrhagia Outcomes study overlapped in outcome measures to an extent. In the future, I would stick with the SF12 or updated similar questionnaire for measures of functioning. I think that the volume of questions contributed to the missing data as I found that some participants had returned the questionnaires half completed particularly the Menorrhagia outcomes one.

I have however learnt a great deal by using all these questionnaires in how to code them and analyse them as well as how to present their results and draw conclusions. With this study, the aim of using the questionnaires was to triangulate the interview findings; hence a power calculation was not carried out for rigour of statistical analysis. Now that I am familiar with the methodology of administration and analysis of these questionnaires, I feel that I would know how to use them in larger studies if required where I could ensure the study was powered enough to answer the question.

I have also learnt how to conduct a systematic review using software such as RevMan, how to critically analyse the literature and how to interpret and present the results in forest plots. Since starting my MD, I have successfully co-authored a Cochrane systematic review and a National Guideline as a result of the skills I have learnt during this MD. Other software I am now familiar and confident in using is SPSS and reference management software, which I now use as a matter of routine in many aspects of my work, such as writing reports which require references, conducting literature reviews to

inform my clinical practice and evaluating services and therapies using statistical analyses.

Conclusion

Individual psychological wellbeing and any post-operative complications have the most significant effect on recovery and programmes should be developed to target recovery outcomes by enhancing education, empowerment and a more positive psychological state. In order to reduce confusion, there should be a consensus amongst health care workers of recovery expectations and when to predict variations from normal recovery.

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Appendices:

